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World Mental Health Day 2014



LIVING WITH **SCHIZOPHRENIA**



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FOREWORD

“Living with schizophrenia”, the theme we chose for the 2014 Mental Health Day, can be approached from a variety of perspectives. Let me mention some.

Who lives with schizophrenia? First of all, the people who suffer from it. It does not matter whether it is an illness or a disorder, whether you call it schizophrenia or integration dysfunction, whether you refer to the people who suffer from it as patients, service users or consumers. What matters is that they suffer from it to an unbelievable degree and that the rest of us who are lucky to have escaped from it have a moral obligation to show solidarity and help. We must not forget two things. First, that it is within our philanthropic, advocacy, professional and social roles to do that and, second, that no one is immune to mental illness including ourselves and our families. By helping people with schizophrenia and by promoting prevention, treatment and research into this condition we help ourselves.

Some people, even professionals, believe that schizophrenia expands the spectrum of human experience; it may even bring people closer to spirituality. They believe that persons with this disorder have historically initiated new religions and spiritual movements, they have opened new paths in the perception of the essence and the scope of living, and they have developed novel philosophical theories. This is true, they can certainly do all these things, but not to a greater extent than non-sufferers. What really differentiates them from other human beings is the degree of psychological pain they experience, an intense, long-lasting and often unbearable pain. A measure of the intensity and persistence of this pain is the self-destructive potential of the patient. The pain is coupled with a perception of social isolation produced by the stigma attached to persons with schizophrenia and the resulting institutional way of treatment that still prevails in many parts of the world.

So, the main categories of people who “live with schizophrenia” are the patients themselves. There are, however, others who also live with it. These are the family members, the carers. They also have to live with this disorder, they know it well, they know its manifestations and they usually know how they can co-exist with it. The help from the family is usually superior to even the best hospital or community facilities, especially in certain family-centered cultures. Yet, there is a price to pay for this. And this is the impact of schizophrenia on the health of family members and carers. The burden of schizophrenia also falls on them.

Professionals also “live with schizophrenia”. Some of us have dealt with this illness all of our working lives. We know the early signs and symptoms, the multiple and changeable ways

in which it is clinically expressed, the resulting difficulties in detecting and diagnosing it, the risks associated with it, the difficulty of patients and relatives in coming to terms with it, the social stigma attached to it, the discrimination experienced by the sufferers, the difficulties in rehabilitation and social re-integration, the problems in adherence to and compliance with treatment. We also know that the management of persons with schizophrenia has been very bad in the past and is still bad in many parts of the world and that there have been dark periods in the history of humanity during which the patients have been mistreated and ridiculed. Additionally, we know that in practically all parts of the world a great proportion of patients do not receive treatment at all.

Fortunately, during the 1950s, modern psychopharmacology developed novel effective medication and the community mental health movement appeared. These two developments increased the therapeutic potential and contributed immensely to more humane treatment of patients. De-institutionalization (chronic patients living in the community instead of institutions) became possible and occupational rehabilitation was implemented in a number of patients. Today the treatment of people with schizophrenia is more person-centered, more collaborative and more effective. Acceptance and implementation of concepts like positive mental health, recovery and resilience have had a decisive influence on the mentality of professionals and the public. A very positive development was that the patients have been empowered and have developed a voice of their own and the capacity to decide about their future in an autonomous way. Autonomy is now a key word in the ethics guidelines of most mental health professional ethics codes, and although there are cultural differentiations the trend is towards the direction of its universal acceptance.

Advocates and advocacy organizations like the World Federation for Mental Health also live with schizophrenia, in a sense. They try to identify with the patients, to feel their needs, to side with them. The key word is EMPATHY. Advocacy organizations have an important role to fulfil and this role is to strive for improved patient care and defend the patient’s rights. One of the most realistic goals of advocacy groups is to underline to politicians and the public that care for the mentally ill is cost-effective. This is the language that politicians understand. Lastly, “Living with Schizophrenia” has yet another perspective if we think of the effect of this illness on the general population, that is, on SOCIETY as a whole. Society also lives with schizophrenia.

FOREWORD (continued)

The response of society to people with schizophrenic illness has not always been kind. If we think of the way in which mental patients, and particularly patients with this diagnosis, have been treated in medieval times and are still being treated to-day in certain cultures, it will not be difficult to realize that in spite of the progress noted in the last years much more has to be done. Stigma and discrimination play an important role in the shaping of the attitudes of society towards mental illness and towards the persons who experience it.

In conclusion, the people who “live with schizophrenia” belong to various categories—consumers, carers, professionals, advocates and society as a whole. It is the dynamic collaboration and synergism between these groups (“Working together for mental health”) that will make “Living with Schizophrenia” worth living.

The topics in this collection of papers were chosen to reflect the experience of “living” with the illness but also the basic scientific facts about it. We have to know what we are talking about and this knowledge should be evidence-based. The concept of “recovery” is important but it has variable limitations. It is not a substitute for treatment but acts in dynamic synergy with it. Schizophrenia is a severe, potentially incapacitating illness that affects a considerable segment of the population. About 0.7% to 1.0% of the population globally is affected by this condition, not counting those who belong to a broader schizophrenic spectrum, and those who are indirectly affected by it. It is estimated that at least 26 million people are living with schizophrenia globally. People with schizophrenia die 15-20 years earlier than the general population (mainly due to co-existing physical illness and smoking); they are 6-7 times more likely to be unemployed; they are very often homeless and in contact with the criminal justice system; and 5-10% take their own life. According to the World Health Organization, schizophrenia is one of the leading causes of disability globally.

However, the above facts about the severity of schizophrenia should not lead to pessimism. Modern methods of treatment, both biological and psychological, coupled with a change of attitude in society about mental illness, have led to very impressive changes that have allowed “Living with Schizophrenia” to be a positive and productive experience for many persons. Many more can live in the community with some symptoms that do not substantially prevent them from leading a normal everyday life. Self-help groups and advocacy organizations (like our WFMH) have contributed considerably to these positive developments.

Schizophrenia has been characterized by some (for example the UK Schizophrenia Commission) as “the abandoned illness”. This is probably a hyperbolic statement but underlines the need to pay more attention to this disorder and to the people who experience it. Focused research, advocacy, funding of mental health services (at least to the level of funding for physical health), integration of persons with schizophrenia into society, opportunities for occupational rehabilitation, diminishing of stigma and discrimination, safeguarding the human rights of people with this illness—these are some of the actions that should be taken. This collection of papers represents one of the contributions of the WFMH to the effort.

I wish to express my thanks to the WFMH Executive Committee, to our World Mental Health Day Committee (chaired by Patt Franciosi), to our WFMH Public Impact Committee (chaired by Gabriel Ivbijaro), and to our staff members Deborah Maguire and Elena Berger. I wish to thank Lundbeck for having supported us with an unrestricted grant to achieve our public education goal, and Otsuka for its generous support. I appreciate an unrestricted grant from F. Hoffmann-La Roche Ltd. which supported the project. I would also like to thank the contributors to this collection of papers, all of them experts in their field, for putting their expertise to the service of this goal. This publication is in line with a WFMH tradition that has existed for many years and we believe has contributed considerably to the advancement of global mental health.

Translations extend the reach of the project. For arranging the translation of the material into Arabic, I wish to thank His Excellency Dr. Abdulhameed Al-Habeeb, Director General of Mental Health, Saudi Ministry of Health and Dr. Abdullah Al-Khathami; for Chinese, Sania Yau, New Life Psychiatric Rehabilitation Association, Hong Kong; for Hindi, Dr. M.L. Agrawal and Dr. Aruna Agrawal, Directors of Agrawal Neuro Psychiatry, India; and for Russian, AstraZeneca Russia.

Lastly, I wish to thank Hugh Schulze and his communications, graphic design and web development company clchange in Chicago for their design of this publication and for their design and support of the WFMH website.

Prof. George N. Christodoulou
President
World Federation for Mental Health

It wasn't that long ago that many people considered schizophrenia a chronic, progressive illness that meant people's dreams had to permanently be put on hold. Today, schizophrenia is no longer an automatic life sentence. A growing cadre of consumers, researchers and healthcare providers now say recovery is not only possible, it is a natural right of those diagnosed with the illness.

Barrett R.

Turning the Corner: Hope is about recovery and resilience.

Schizophrenia Digest

2003Spring: 38-39

Dear Friends and Colleagues:

The World Federation for Mental Health (WFMH) has chosen the theme "Living with Schizophrenia" for its 2014 World Mental Health Day campaign in order to highlight changes in current thinking about the illness. WFMH established World Mental Health Day in 1992; it is the largest program of the Federation and its aim is to draw attention to important mental health issues. World Mental Health Day is observed in many countries in all parts of the world on October 10 with local, regional and national public awareness events.

This year we are taking advantage of these observances to let people know about important changes in the way mental health professionals view the illness. At least 26 million people are living with schizophrenia worldwide according to the World Health Organization, and many more are indirectly affected by it. The illness affects a person's well being, shortens life and is among the top causes of disability globally. It is often neglected and misunderstood. It imposes a heavy toll on the individuals who experience it, and their family members and caregivers. And the high level of stigma associated with schizophrenia is an added burden.

While the illness is severe, new approaches are resulting in improved outcomes over time for many who have it. A challenge facing the mental health advocacy community is to create public pressure to change national mental health policies around the world, so that they take into consideration the scientific, clinical and social advances of recent decades. It is our aim to improve public understanding of schizophrenia and draw attention to ways in which better care can be provided.

We also want to draw attention to the needs of family members and other caregivers. And we want to draw attention to the possibility of recovery.

This campaign will discuss how to improve public education, raise awareness, reduce stigma and discrimination, and promote service and policy advocacy to address the impact of schizophrenia on the global burden of disease.

We thank you for your continued efforts to promote mental health awareness in your communities by taking part in the annual World Mental Health Day campaigns. Your local efforts will be the key to lasting change in the way people with mental health issues are treated, and to improving the opportunities they have in life. Thank you for all that you continue to do for global mental health!

Dr. Patt Franciosi

WMHDAY Chair

WFMH Board of Directors

SECTION I

LIVING WITH SCHIZOPHRENIA

WHAT IS SCHIZOPHRENIA?

Schizophrenia is a serious mental illness that affects how a person thinks, feels, and acts. Many people find it difficult to tell the difference between real and imagined experiences, to think logically, to express feelings, or to behave appropriately.

Schizophrenia often develops in adolescence or early adulthood and affects approximately 26 million people worldwide.¹ People with schizophrenia experience a range of symptoms that may make it difficult for them to judge reality. While there is no cure for schizophrenia at the moment, treatments are available which are effective for most people.

Not everyone who is diagnosed with schizophrenia has the same symptoms.² The definition of the disorder is quite wide, includes many different possible combinations of symptoms, and can vary across countries. Schizophrenia will normally be diagnosed by a psychiatrist, but there are many symptoms which occur in schizophrenia that everyone can be aware of. For some people, schizophrenia begins with an “early psychosis” or “prodromal” stage. Key features of this stage include:

- Sleep disturbance
- Appetite disturbance
- Marked unusual behaviour
- Feelings that are blunted (flat) or seem incongruous (inconsistent) to others
- Speech that is difficult to follow
- Marked preoccupation with unusual ideas
- Ideas of reference – thinking unrelated things have a special meaning, ie, people on TV talking to you
- Persistent feelings of unreality
- Changes in the way things appear, sound or smell

Some people may experience early psychosis or a prodromal stage and never develop schizophrenia. Others who develop schizophrenia never show signs of early psychosis/prodrome and therefore have no option for early treatment, while there are people who have symptoms and obtain early treatment but nevertheless go on to develop schizophrenia. Symptoms which may then occur are often grouped in to three categories: positive, negative and cognitive. The terms “positive” and “negative” can be confusing. Essentially, positive symptoms suggest that something is present which should not normally be there. A negative symptom is something that is not present, but should be.

Schizophrenia can occur anywhere, and affect anyone. However, variations exist in the numbers of people diagnosed in different communities, the symptoms that they experience, how they are diagnosed, and how different communities view and react to someone who has schizophrenia. There is also significant inequity in access to treatment for people with schizophrenia depending on where they live. The World Health Organization reports that more than 50% of people with schizophrenia cannot access adequate treatment, and 90% of people with untreated schizophrenia live in the developing world.

Schizophrenia is a treatable disorder. For the millions of people worldwide living with this disorder, there are treatments that can help to reduce symptoms and improve the ability to function at home, at work, and at school. For many people, long-term medication is necessary but a number of other treatment options/ services may also be helpful including talk therapy, self-help groups, vocational rehabilitation, community programs and peer-support. People with schizophrenia should work with their healthcare professionals and families to develop a treatment plan that works for them.

References:

1. Schizophrenia. Geneva (Switzerland): World Health Organization; www.who.int/mental_health/management/schizophrenia/en/
2. Schizophrenia Society of Canada. Basic Facts About Schizophrenia: Families Helping Families. Ontario (Canada): Schizophrenia Society of Canada; 2002. 27p.
4. Schizophrenia Handbook.

SCHIZOPHRENIA: IT'S STILL PRETTY MUCH WHAT IT USED TO BE

Jeffrey Geller, MD, MPH

A bold statement: The progress in our understanding of schizophrenia, with one fundamental exception, has advanced surprisingly little in the past half century.

Schizophrenia is a set of symptoms psychiatry has labeled as a disorder. According to DSM-IV-TR (the Diagnostic and Statistical Manual of Mental Disorders, text revised, published by the American Psychiatric Association in 2000), the diagnostic criteria for schizophrenia are : Two (or more) of the following, each present for a significant portion of time during a 1-month period (1) delusions (2) hallucinations (3) disorganized speech (4) grossly disorganized or catatonic behavior (5) negative symptoms, i.e., affective flattening, avolition (poverty of speech), or avolition (lack of motivation). Only one of these symptom is required if delusions are bizarre or hallucinations consist of a voice keeping up a running commentary on the person's behavior or thoughts, or if there are two or more voices conversing with each other. For a significant portion of the time since the onset of the disturbance, one or more major areas of functioning such as work, interpersonal relations, or self-care are markedly below the level achieved prior to the onset. There have been continuous signs of the disturbance persisting for at least six months.

Thirteen years later, in DSM 5, there were no major changes in the diagnostic criteria. In DSM 5 two or more symptoms are always required and the subtypes of schizophrenia have been deleted. Subtypes had been defined by the predominant symptom at the time of evaluation, but these were not helpful because patients' symptoms often change from one subtype to another over time and there are all too often overlapping features amongst the subtypes. The etiology of schizophrenia remains outside our reach. While we have moved beyond the "schizophrenogenic mother", theories of etiology are about as wide-ranging as one can imagine: prenatal influenza or other prenatal factors; a determined enzymatic error, such as one causing episodic or continuous formation of endogenous 6-hydroxydopamine or a novel mechanism for regulating dopamine

activity ; postnatal brain injury; early childhood trauma; or *Toxoplasma gondii* , an intracellular, parasitic protozoan.

A major step forward in the treatment of schizophrenia occurred in the mid-1950s when chlorpromazine became available. There followed a series of other medications, all with quite problematic side effects, many in the category of extrapyramidal side effects, e.g., haloperidol, thiothixene, perphenazine, trifluoperazine. Thirty-five years after chlorpromazine, a new generation of antipsychotic medications was introduced by clozapine, to be followed during the 1990s by olanzapine, risperidone, and quetiapine, with ziprasidone and aripiprazole coming along in the early 2000s. Initially touted as both more effective and with fewer problematic side effects based on efficacy studies, when put to general use neither claim for the atypical was entirely born out (with clozapine being the sole exception). In the last 10 years or so, the third generation of antipsychotics has become available, e.g., lurasidone, paliperidone. Whether these are any more than "me too" drugs remains to be seen. All these medications treat symptoms; none address the cause of schizophrenia or offer a cure.

So, schizophrenia is a group of symptoms that may be one or many diseases; has a yet to be determined cause; and has a cornucopia of medications that can treat its symptoms, but at the cost of significant side effects. Not a pretty picture.

While none of this sounds overly hopeful, the fundamental shift in our thinking about schizophrenia concerns its course. Once thought of as dementia praecox (premature dementia) or labeled the "cancer of psychiatry" with a downward course to, if not oblivion, then to the back wards of a public psychiatric hospital, schizophrenia is now thought of as a disorder that an individual can manage, with a combination of treatments, in order to live a life in recovery. According to the US Substance Abuse and Mental Health Services Administration (SAMHSA), recovery is "a process of change through which individuals improve their health and wellness, live a self-directed life, and strive to reach their full potential." A person with schizophrenia can be a person in recovery.

While psychiatry struggles to understand the causes of schizophrenia and works for cures, persons with schizophrenia can be contributing individuals in the mainstream of society. Even some aspects of stigma against those with schizophrenia are waning. Not long ago, if one encountered a lone passerby talking out loud and gesticulating enthusiastically, one thought, "He's crazy." Now, we pay that person no mind—he's just another denizen of our community talking on a hands-free cell phone.

Jeffrey Geller, MD, MPH

Medical Director, Worcester Recovery Center & Hospital

Professor of Psychiatry, University of Massachusetts Medical School

THRIVING NOT JUST SURVIVING

Janet Meagher, AM

Surviving

It won't surprise you to hear that a particular person who had multiple mental health crises, innumerable admissions to acute psychiatric hospital wards, sometimes lived in 'halfway house' group settings, who had times of homelessness, experienced many abusive attacks as well as physical, sexual and emotional assaults, who spent the greater part of a decade in a large psychiatric institution, was confused, traumatized, alienated and antisocial. Opportunities for recovery and rehabilitation were severely impacted by these experiences.

The process of deterioration during that part of the individual's life was clearly a process of acquiring a range of emotional traumas and personal damage from which anyone would be unlikely to emerge unscathed. Looking at this person as an individual human being, we can observe layer upon layer of harm, trauma and lifelong impacts resulting from the experiences of the processes they were drawn into because of developing a mental health problem. Schizophrenia alone was not responsible for the traumas described or for the person's subsequent confusion, alienation and isolation. These are the external personal consequences that impacted on her because she was unlucky enough to develop a severe mental illness. It is these elements that we can address and eliminate from the processes of treatment and support to enable future opportunities for the person living with schizophrenia to lead a contributing life.

Yet the schizophrenia was (and potentially still is), in this person's experience, layered on top of this external trauma creating its own additional horrendous and utterly unbearable burdens. These burdens are the ones that totally crush people. The personal experience of schizophrenia convinces those of us who live with it that it is unbelievably adept at dehumanizing us, creating vulnerability and expunging from us any ability to develop or nurture hopes or dreams, erasing our trust, eliminating our sense of personal capacity and our intelligence, leaving us as remnants, a human shell, devoid of the surety of emotion, of a meaningful

personal capacity to communicate, or ability to confidently relate with anyone else.

People living with a variety of traumas connected to the experience of schizophrenia will find at this stage of the progress of their disorder that they have become reluctant experts—experts whose expertise has had to be developed through their awful task of having to deal with the grief of multiple losses of elements that constitute what it is to be human.

Such losses may include some or all of the following – losing credibility, rationality, capacity to communicate effectively or coherently, loss of reputation, of friends, of family, loss of educational opportunities, of jobs or employability, or your home, your things, your potential, a family of your own. Loss of physical fitness, losing your looks, developing poor health, loss of your future and often your community connections.

'We found ourselves undergoing that dehumanizing transformation from being a person to being an illness: "a schizophrenic" Our personhood and sense of self continued to atrophy as.... our sense of being a person was diminished as "the disease" loomed as an all powerful "It" that we were taught we were powerless over.... The self we had been seemed to fade farther and farther away, like a dream that belonged to somebody else. The future seemed bleak and empty and promised nothing but more suffering. And the present became an endless succession of moments marked by the next cigarette and the next. So much of what we were suffering from was overlooked. The context of our lives was largely ignored. The professionals who worked with us had studied the science of physical objects, not human science'. Patricia Deegan, "Recovery and the Conspiracy of Hope," TheMHS Conference 1996, Brisbane, Australia.

The person living with schizophrenia is an enigma, because their mere survival bestows upon them a hero status.

Of necessity, they have had to deal with a plethora of loss, of trauma and of personal and emotional distress yet they keep going, they find ways through their struggles, and their efforts see them

manage their lives and often develop new friendships and ways of coping. Above all, they survive.

Anyone who can find their way through the personal mess and the emotionally charged losses that accompany a life lived with schizophrenia, is, in my judgment, a real hero. The singular effort and courage involved in living and surviving from day to day is, without exception, a hero's journey. This is never fully realized by the clinical or personal helper. My belief is that you need to have an understanding of the effort required for the person to survive from hour to hour, to maintain that last glimmer of their life force and nurture it with the secret remnant of potential lying dormant in their heart. At this time and in this personal space this is an absolute miracle. A flickering of this shows the observant one that there is a spark that needs fuel and acknowledgment of what is possible for that person, that hero.

"It may be that some root of that sacred tree still lives, nourish it then that it may leaf and bloom and fill with singing birds." (Black Elk, Native American Chief)

As the author of this article I have used my personal experiences and understandings of schizophrenia within my own life as my primary reference source. I've lived with schizophrenia since my early twenties and have reached the stage where I'm very confidently managing to live a fulfilling life with my remaining symptoms integrated into my life without substantive negative impact. I have accepted schizophrenia and no longer deal with it as a problem needing to be 'treated' or eliminated but as a 'normal' aspect of me that merely needs to be managed and monitored by me. This mindset is hard to practice and learn but makes for a great quality of life and the ability to reach some of my remaining potential.

The result is that I've become a person who lives a full and rewarding life. I am able to contribute at the highest level of government, and at local, state, national and international mental health involvements with enthusiasm and vigor. In this work I particularly lobby for enhanced recognition and respect for those people across the world who live with mental or emotional distress. In mental health work, ethical processes

ought to demand that there should be “Nothing about us without us,” and if that were so there would be more respectful and humane policies, attitudes and services and less damaging misunderstandings. Ultimately there would be genuine consumer/user/survivor participation as well as enhancement of and recognition of people’s human rights in all treatment, psychosocial and professional development settings.

With the right encouragement and building on an individual’s capacity, good things begin to happen.

Frequently people living with schizophrenia, with the right opportunities, will be able to do more than merely survive—they will thrive.

Thriving

For the person living with schizophrenia who wants to move beyond surviving to thriving we will need to ascertain what would help or hinder that person embarking on that journey. If schizophrenia is my life companion I need to find ways forward so that its impacts on my life are lessened, so that this ‘burden’ can be dealt with, managed and minimized in order for me to deal with and overcome the impacts of the external traumas and consequences. The way forward is to develop a hope-filled mindset.

Today’s understanding of moving forward with hopes and dreams is called a journey of recovery.

‘Recovery does not refer to an end product or result. It does not mean that one is “cured” nor does it mean that one is simply stabilized or maintained in the community. Recovery often involves a transformation of the self wherein one both accepts one’s limitation and discovers a new world of possibility. This is the paradox of recovery, i.e., that in accepting what we cannot do or be, we begin to discover who we can be and what we can do. Thus, recovery is a process. It is a way of life.

It is an attitude and a way of approaching the day’s challenges. It is not a perfectly linear process.... recovery has its seasons, its time of downward growth into the darkness to secure new roots and then the times of breaking out into the sunlight. But most of all recovery is a slow, deliberate process that occurs by

poking through one little grain of sand at a time’. Patricia Deegan, “Recovery and the Conspiracy of Hope”. TheMHS Conference 1996, Brisbane, Australia.

If we look at an ongoing journey to “recover” or deal with the impacts of living with schizophrenia, my journey requires that....

- I understand controlling my symptoms is possible; I embrace them but sideline them and learn ways of dealing with them, so that they no longer dominate my life.
- I dare to hope for a fulfilling life.
- I am able to take risks and learn from my actions.
- I can develop effective strategies to overcome my symptoms and disorganized tendencies.
- I can love and be loved by others regardless of my diagnosis or social shortcomings.
- I ought to participate because I have ideas and can offer inputs that are of value. Others should encourage this to develop confidence and bolster self esteem.
- I experience a usual range of stress, and need to plan for ways to overcome difficulties and document my progress with challenges.
- I can live independently and manage my life needs—with support from time to time if necessary.
- I am employable and able to aim at earning and supporting myself.
- I am able to overcome the traumas and damage to my life and contribute to my community.
- I can hope and dream for the same ideals and opportunities, as others are free to do.

Attitudes of the support people are pivotal to the success of this process. The offering of appropriate and empowering supports is the only things which will enable a person to begin to thrive. It will be a slow but effective awakening with consistent support. I was drawn through such a process and my fellow peers living with schizophrenia also deserve the same opportunities to live a fulfilling and rewarding life.

We deserve not just to survive, but to have opportunities to thrive and to live a contributing life.

Janet Meagher AM

Consumer Activist

National Mental Health Commissioner (2012-2013) Australia

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LIVING WITH SCHIZOPHRENIA

Bill MacPhee

I have been living with schizophrenia since 1987, from the age of 24. I was hospitalized six different times, lived in three group homes, and had a suicide attempt. I suffered with positive symptoms such as paranoia, delusions, thinking that I could read other people's minds, voices and hallucinations. I have dealt with negative or deficit symptoms such as lack of motivation and energy, lack of joy and blunted effect on my emotions, as well as depression. Schizophrenia was the hardest challenge to deal with in my whole life.

There is life after mental illness.

Today I consider myself as a recovery expert and my definition of recovery is when you would not want to be anyone other than who you are today. This definition is meant for all of us, not just people with mental illness or schizophrenia. Today I am married, have three children and run a small publishing company (www.magpiemags.com). I am active in my community and speak throughout North America. Was it easy? No. It takes living one day at a time, and always moving toward a better quality of life.

I have talked to hundreds of people dealing with mental illness and what is most important in order for people to recover is opportunity. People need to find and identify opportunities that exist to find a start and move in the right direction for a better quality of life. One thing that is important for individuals, family members and people who may be caregivers is that you cannot make the initial decision for someone else. A person needs to want a better quality of life, but remember that you have to separate someone's lack of ambition from a lack of self-esteem. Everyone who has a mental illness, at one time or another, deals with a lack of self-esteem. We are very fragile people, but we must not beat ourselves up as we start to recover our self-esteem, and our confidence will come back.

My medication works for me. It was a trial and error process but with my medication I have no positive symptoms

of schizophrenia, but that is only half the battle. Once we get stable we need to work on psychosocial issues such as our social skills and building our support system. We need to come out of our isolation and make a life for ourselves, which I will admit is easier said than done, but it is crucial. This may sound blunt but many people need a life. Remember the saying "Get a life"? Well that is exactly what we need to strive for; we need to get a life. In other words, what happens is that we get stuck. In my case I was on the couch for five years thinking of ways to kill myself and having no life at all. I was stuck. But I did know what scared me. It was that five years turning into seven and ten years. I use to say if things don't change they will stay the same, if things don't change they will stay the same. I hated my same. I knew I needed to create a spark. I needed a life.

At this time I was dealing with self-esteem issues and I remembered what a grade 7 school teacher said to me. She said "Bill, if you do not learn to write properly you will never amount to anything in life." My penmanship was like chicken scratch. Remembering that, I said to myself 'I am going to prove to someone that I can do something.' So I took the initiative to contact the literacy foundation in my hometown and told them that I could read and write but my penmanship was very poor and I wanted a tutor. This was my turning point. My tutor got me socializing and making friends and helped me by asking if I would help out in the scouting movement. From that point on I met friends and started to get active and invest myself in the community, which again was my turning point.

There is life after mental illness. For the last 20 years I have been publishing SZ Magazine and just published my autobiography and memoir called "To Cry a Dry Tear: Bill MacPhee's journey of hope and recovery with schizophrenia".

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LIVING WITH SCHIZOPHRENIA: A PERSONAL STORY

Dr. David Crepaz-Keay

Living with schizophrenia, the first 35 years....

I've been living with my diagnosis of schizophrenia for over 35 years now. I got it when I was a teenager. It wasn't my first diagnosis but it was the one that stuck. When I first got it, I thought my life was over. I was studying for exams and I wanted to be an economist. I didn't think anyone would want a schizophrenic economist.

Expectations

I wasn't alone in thinking that. One of the things that struck me most was the low expectations that followed. This was particularly apparent amongst medical staff, all they saw was a label—the person I used to be, or might become, vanished. If enough people, particularly professionals, treat you like a lost cause, then sooner or later you end up believing it. I was fortunate that people who really understood my experience still expected me to achieve things. One in particular persuaded me to get actively involved in a local support organisation, expecting me to get on and do things for myself and others rather than becoming a passive patient.

Friends and relationships

Fortunately I had friends who believed in the old me. I also developed new friendships with people, many of whom had shared my experiences of psychiatric care. Spending time with people who shared my experience, but had survived and thrived in spite of it, was an inspiration and many of these people remain good friends to this day. Not all my friends were able to cope with me and sometimes I felt very lonely and isolated, but there were times when it was only my friends that kept me going.

Treatments and services

Attitudes towards treatments were often unhelpful. It should be simple, the treatments either help or they don't. If they do, that's good. People should have access to the best available; if they don't, it's no one's fault and treatments that don't work shouldn't be forced on people. Self-help, self-management and peer support are starting to help a lot of

people. They have helped me and have given me the ability to help others.

Jobs

My work has always been important to me, both before my time working in mental health and since. I have not always been able to work, and my best employers have been very supportive when I have been at my most unwell. Although work can sometimes be stressful, I have always found being out of work much worse. My work has given my life meaning and purpose, a chance to contribute.

My work in mental health has enabled me to take my experience of mental ill-health and use it to help others. I have had the opportunity to meet many people who have been directly affected by mental ill-health and still achieved great things. Together we have become part of an international community and are stronger for it.

Future

When I first got my diagnosis, I thought my life was over. Now, 35 years later, I just think it's part of who I am. The people I care about, the people who matter, don't see a diagnosis, they see a person. It's been an interesting 35 years and I'm looking forward to many more.

Dr David Crepaz-Keay

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SECTION II

HEALTH PROMOTION & PREVENTION IN SCHIZOPHRENIA

HEALTH PROMOTION IN SCHIZOPHRENIA

Dr Nikos Christodoulou,
Prof Dinesh Bhugra

Introduction

The World Health Organisation defines health as “a state of complete physical, mental, and social well-being and not merely an absence of disease or infirmity”¹. This definition captures two crucial points:

Firstly it emphasises that mental health is an inseparable part of a person’s holistic well-being, together with physical and social health. This latter point of the indivisibility of body and mind is ancient; “mens sana in corpore sano” (healthy mind in a healthy body)² and also “τίς εὐδαίμων, ὁ τὸ μὲν σῶμα ὑγιής, τὴν δὲ ψυχὴν εὐπορος, τὴν δὲ φύσιν εὐπαίδευτος” (Who is happy? He who has a healthy body, a resourceful soul and a docile nature)³. In addition to notable elaborations in the literature^{4,5}, recent years have seen the elevation of this philosophical stance into a campaign, for instance the “No health without mental health” campaign, endorsed by the World Psychiatric Association, the Royal College of Psychiatrists and the Department of Health for England, among others. Promoting mental and physical health together is the right thing to do, especially in schizophrenia, especially if one takes into account the physical co-morbidity associated with it. However, in the past it has been noted that mental illness prevention and mental health promotion have received less attention than the physical health needs of people with mental illness⁶.

Secondly, the WHO definition asserts that illness prevention is necessary, but not enough to achieve health⁷. This concern is underpinned by the fact that psychiatry has focused on illness rather than well-being and good functioning⁸; indeed,

health promotion is also necessary in addition to prevention. In fact it becomes even clearer how necessary it is if we just listen to what people who suffer from schizophrenia actually want: They do want to get on with their lives which means having jobs, friends, housing and money even if they continue to have symptoms. The challenge for psychiatrists is to combine treatment as well as prevention but equally important to advocate for our patients and help promote mental health.

Listening is only one part of communication between the clinicians and their patients; the other is delivering a clear message which is easily understood: We aim to do just that in this piece. This is hopefully a clear and informative introduction to health promotion in schizophrenia. It is written for a wide audience, including those who suffer from the illness, their carers and families, and healthcare professionals alike.

Illness Prevention and Health Promotion in Schizophrenia

Schizophrenia is one of those life-changing illnesses, but it does not have to be life-defining. Just like people with diabetes, hypertension, rheumatoid arthritis or heart disease, people with schizophrenia frequently have to keep their illness at bay with medications, life-style changes or psychological therapies or a combination of those. But beyond illness, and certainly more importantly, people with schizophrenia have a life to live and enjoy. It may be with small steps initially, but focusing on the positive aspects of one’s life builds on strengths and leads to an upward spiral of positivity. By focusing on this - the positive and healthy aspects of their life – people who suffer from schizophrenia begin to gain confidence and self-esteem and become more independent and empowered in their life. Eventually, they can start defining their life and themselves as persons rather than patients and start

focusing on their health rather than their illness. By doing so, they enhance their ability to achieve psychological well-being and also cope with adversity⁹.

While this approach can yield great rewards for people with schizophrenia, managing to adhere to it is easier said than done. The difficulty lies in that one needs to keep their illness at bay while focusing on the positive aspects of their life. Keeping the illness at bay is complicated by the fact that schizophrenia is one of the few illnesses that affect the person’s ability to recognise that they, in fact, have an illness. Lacking that insight makes people believe that they don’t need therapy, be that with medications or any other kind, and slowly but surely the illness returns with a vengeance. This tension can create major problems with carers as well as health care professionals. That is why it is very important for people with schizophrenia to remember that, in addition to their own individual strengths and virtues, they also have an illness that needs to be tamed in the same way as other chronic conditions are managed.

Focusing both on prevention and promotion can serve to help in multiple ways: Improving one’s health can lead to preventing mental illness and vice versa. As shown in the case of depression¹⁰, people with low positive health can be vulnerable to illness, and conversely, by increasing positive mental health one may also manage to prevent illness¹¹. Using prevention and promotion makes logical sense; on the one hand prevention is better than cure, and on the other hand improving one’s life is an end in itself. Furthermore, mental illness prevention and mental health promotion are supported by mounting evidence on their effectiveness and cost-effectiveness, which is reflected in the fact that they have been endorsed by major bodies such as the European Parliament¹² and the World Health Organisation¹³.

Health Promotion May Be the Most Important Intervention in Schizophrenia

Some people with schizophrenia experience a gradual decline in their ability to function at a high level. This is due to a number of factors some of which are intrinsic to schizophrenia, including, for example disorganisation and depression, but others are to do with stigma and social exclusion. For those who experience it, this functional decline can be very frustrating, especially as it is often persistent. Treating schizophrenia appropriately means that some of the symptoms may go away, but even that does not guarantee that the person's life experience will improve. A characteristic example of this is depression in schizophrenia: There is some older evidence suggesting that depression can be a good prognostic factor for schizophrenia. Indeed, this is often seen in clinical practice, where an affective component may predict better response to medications. However, more recent evidence suggests that, while the presence of depression may be good for the prognosis of the illness, it is not good for the person, as it is associated with poorer recovery¹⁴, more relapses¹⁵ and generally a drop in quality of life¹⁶. In other words, treating schizophrenia in these cases may be relatively easier but regardless of whether the treatment is successful or not, the person still suffers with a lower quality of life.

Therefore, as demonstrated in the case of depression in schizophrenia, treating the illness is not enough to achieve true quality of life. Preventing the illness from occurring in the first place (primary prevention) would be a very attractive option, as symptoms and functional decline would not have developed yet in these early stages. However, as a practical matter, in most cases prevention in schizophrenia is tackled at a secondary or tertiary level, i.e. once the disorder has already taken hold or has already caused symptoms and/or functional decline. In fact, one of the main difficulties in recognising schizophrenia at primary preventive level is that it is exactly those symptoms that reveal it, and therefore

almost by definition it is very difficult to "catch" it early. Regardless of that, preventing relapses and consequences of the illness (secondary and tertiary prevention) can be useful, as preventing relapses also prevents further functional deterioration, and consequently improves quality of life. Although the usefulness of prevention may be rather limited for those who have already had functional decline, health promotion can still play a key role.

In order to improve quality of life for patients, a different approach is needed, and that would be to reinforce those factors in a person's life that would empower them to build on their own strengths and improve their quality of life, regardless of the state or stage of their illness. Health promotion can be applied way before the illness manifests itself and will contribute towards primary and secondary prevention as a bonus effect. An excellent example is Early Intervention in psychosis, a practice that has great potential not only for preventing the onset of frank illness for young people with prodromal symptoms, but also for longitudinally influencing their health and quality of life¹⁷. Even for those who will not go on to develop schizophrenia, population-targeted mental health promotion can lead to an improvement in well-being and quality of life. Being aware of the stressors which can cause any number of psychiatric illnesses and relapses can help a person. Focusing on promoting health in addition to preventing/treating the illness allows us to achieve an improvement in quality of life irrespective of the illness.

A very important conceptual point that emerges from this approach is that focusing on the promotion of mental health allows us to consider the person – not the illness – as the central and most important entity. Indeed, person-centred medicine itself has developed into an important champion of mental illness prevention and mental health promotion¹⁸. Focusing on the person rather than the illness and applying mental health promotion equally to both the healthy and the ill, helps to push back against the stigma associated with mental illness and psychiatry.

Health promotion in schizophrenia is important not only for the individual, but also for society as a whole. There is good evidence suggesting that illness prevention and health promotion measures in schizophrenia may be both clinically effective and cost-effective¹⁹. Although financial considerations should not come into play at the clinical setting, one cannot escape the realisation that cost-effectiveness coupled with re-investment can improve mental healthcare for all.

Conclusion

In conclusion, health promotion may be considered to be the most important intervention in schizophrenia as it can benefit everyone²⁰, regardless of the state or stage of their illness, can be applied to the wider population, can offer an improvement in quality of life as opposed to the mere absence of illness, and can be cost-effective and therefore indirectly beneficial for the health of many more people. Given the evidence, mental health professionals need to embrace mental health promotion. However it appears that often this is not the case²¹. More effort is therefore required, particularly in order to communicate this message to mental health professionals, but also to patients and their carers and families. To this end, the role of the World Federation of Mental Health is very important and its Mental Health Day is a pivotal event.

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SCHIZOPHRENIA & SOCIAL INCLUSION

John Bowis

Just imagine you have been to your GP (primary care doctor in the UK – General Practitioner) and he has made a diagnosis and you go round to the pub or back to work and say to your friends or colleagues ‘Do you know what – I’ve just been told I have got schizophrenia’.

Do they rally round, put an arm round you, buy you a drink, tell you their granny had it, reassure you that there are good treatments for it nowadays and tell you to keep in touch and let them know how you get on?

Or do they go silent, avert their gaze, remember they have a meeting to get to, slink away to phone home and tell their spouse not to let the children go to your home anymore?

Or do you not go to the pub or back to work or anywhere you might meet your former friends and colleagues, because you’re scared – scared about your condition and scared about their reaction?

Schizophrenia is a no-go word; it is a word that spells stigma – stigma from the rest of the world and stigma from inside you. No wonder campaigns are running to change the terminology – although I’m not sure the proposal of ‘Psychosis Susceptibility Syndrome’ is quite the de-stigmatising alternative we seek.

Whatever we call it, we need to de-demonize it, if we are to succeed in bringing social inclusion to those who live with it.

The first assumption is that you are dangerous. The media choose to portray your condition as violent and a risk to people in the street. The reality is that few have violent episodes and most of those are cases of self-harm. In the UK we have some 250,000 diagnosed cases. Of the 5,189 homicides in Britain over nine years between 1997 and 2005, only some 510, or 10 per cent, were committed by people who had been in contact with the

mental health services over the previous 12 months. In fact you are 14 times more likely to be the victim of violence than the perpetrator.

Looked at another way, 99.97 per cent of people suffering from schizophrenia will not be convicted of serious violence in a given year.

And yet, while an NHS (UK National Health Service) survey on attitudes to mental illness in 2011 showed that 77 per cent of people agreed that “mental illness is an illness like any other”, only 25 per cent agreed with the statement that “most women who were once patients in a mental hospital can be trusted as babysitters”.

The second assumption is that you cannot be treated or cured and so you should not be out of a hospital. The reality is that some 25% of people with schizophrenia do recover fully, a further 25-35% improve considerably and live relatively independent lives, some 20% improve but need extensive support and between 10 and 15% remain unimproved in hospital. A further 10-15% will die prematurely, mostly by suicide.

I have met many people who live with the condition. Some have been in hospital, some have been living independently in the community, some with their families, some have served with me on NGO boards and some are holding down responsible and demanding jobs. Some have few symptoms and some have overpowering ones. They range across the list of positive symptoms, such as hallucinations and delusions, to negative ones, such as withdrawal and lack of motivation, to cognitive deficit, such as loss of attention span and these are well described in the Background sheet you will have seen.

The film ‘A Beautiful Mind’ gave a vivid experience of living with voices, of withdrawal, of family confusion and of ultimate hope, which certainly reflected the lives and emotions I have met.

The key message from my experience and from that film is that this is a condition which can be managed and self-managed with supportive treatment, social care and with doors opening to social inclusion and not slamming shut through the ignorance of pre-judging and stigma.

Social inclusion is a meaningless term unless we break it down into its component parts. It is not just communication and outreach services, although it may involve both. It is listening and respecting and assuming a can-do ability on the part of the individual – or a could-do one, if obstacles were removed and encouragement given.

It is opening doors to advice and advocacy; it is making possible opportunities to work or to volunteer, to take as much responsibility as feels comfortable for now; it means educating media, communities, employers, trade unions, police, health professionals and managers and policymakers to revise old assumptions and old prejudices; it means ensuring the law, regulations and procedures are reviewed and made relevant; it means treating co- and multi-morbidities; it means having a benefits system and housing provision that help recovery and stability and it means caring for the carers and assessing their needs.

It means all of us posing the question to ourselves: ‘If it is me or my child or my spouse or partner, what would I fear, what would I hope for and how could I be helped to cope?’

John Bowis

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THE ROLE OF GOVERNMENT AND CIVIL SOCIETY IN PERSON-CENTERED CARE FOR SCHIZOPHRENIA

Juan Mezzich, MD, PhD

WFMH Vice-President for Governmental Affairs

Person-centered care offers a promising approach to care for people experiencing schizophrenia and other chronic conditions, as it places the person in context at the center of health care rather than considering such persons as just carriers of illness. Person-centered care, by emphasizing a holistic health framework and a recovery-oriented approach, is not only more likely to be effective on a sustained basis but also may help de-stigmatize the persons affected and those who care for them. Health care under this perspective is the responsibility of all involved, i.e., patients, families, health professionals, non-governmental organizations (such as the World Federation for Mental Health) as well as governmental and inter-governmental organizations.

Relevant to this approach is the 2012 Geneva Declaration on Person-centered Care for Chronic Diseases which emerged from the 5th Geneva Conference on Person-centered Medicine (in which the WFMH along with the World Health Organization, the International Alliance of Patients' Organizations and a large group of global health institutions participate). It was released by the International College of Person Centered Medicine and published in the International Journal of Person Centered Medicine (Vol 2, pages 153-154, 2012). It is presented below with permission.

"The 21st century is emerging as the century of person-centered care, and this perspective is especially compelling concerning chronic diseases. As the World Health Organization and the United Nations have recently documented and proposed, every government and component of society needs to act now to combat the growing epidemic of chronic and non-communicable diseases that threaten the lives and quality of living for so many people around the world. What we must emphasize now is that a person-centered approach to the promotion and care of health is crucial to counteract this massive epidemic. People with chronic diseases cannot

be effectively cared for without fully engaging them in their own health. Consequently, we believe that bold new approaches to health promotion and illness intervention need to be developed and integrated in our health systems. Furthermore, the patient needs to remain at the heart of these approaches. Effective public health, clinical, medicinal and technological procedures must be developed and implemented having the whole person at the core within a broad biological, psychological and socio-cultural framework.

Around a third of the world's population currently suffers from at least one chronic disease. More than 60% of deaths in 2008 resulted from cardiovascular, cancer, diabetes and respiratory illnesses. A quarter of these deaths occurred in people under the age of 60. Other chronic diseases such as mental and musculoskeletal conditions have disproportionately high disease burden. Death and disability have a devastating effect on individuals, their families, and the societies they live in, with wide economic consequences.

Four essential components of an effective approach to chronic and non-communicable diseases are:

1. Monitoring both risk and protective factors (intrinsic and extrinsic; biological, psychological, and social)
2. Monitoring well-being, including outcomes for positive health (vitality and resilience despite exposure and adversity) and illness (morbidity and disease-specific mortality)
3. Individual and population-level responses to engagement in health promotion (utilization of resources for health promotion, adherence to prevention programs, level of knowledge of effective health promotion and maintenance practices, as well as obstacles and resources needed for their actual application in life)
4. Health system responses to illness (policies and plans, infrastructure, human resources and access to essential healthcare including medicines and other therapies)

It should never be forgotten that people have risk and protective factors; that people experience vitality and resilience, morbidities and disabilities; that people

select the goals and lifestyle practices that they value and should be cared for by services responding to their needs, goals, and values. Chronic diseases, the services that seek to tackle them, and their wider economic impact ultimately involve persons, each with a unique life story, and a unique outlook on life. This shapes their lifestyle colored by their experiences and environments, including the course of their diseases and associated risk and protective factors.

Effective prevention and treatment of diseases should monitor and promote well-being, and should not be reduced to symptomatic treatment and prevention of diseases and their risk factors, as recognized by WHO's definition of health. Attention to health promotion is also important to motivate adherence to treatment. People are more easily convinced to maintain actively their well being than to restrain from unhealthy practices leading to disease onset and chronicity.

Such a framework of health promotion and illness intervention should take full account of the patient's life goals, values, stories and aspirations. The application of the person-centered approach should always be empathetic, respectful and empowering to enhance the person's functioning, resilience, and well being through joint understanding and joint decision making for clinical care and health-promotion.

Thus, the 5th Geneva Conference on Person-Centered Medicine issues the following recommendations:

- Governments should adopt a comprehensive person- and people-centred approach to integration of health promotion and illness intervention to prevent and control chronic diseases. To achieve this, governments should invest in their health systems recognizing that investment in people's health is investment in social welfare, economic prosperity and security.
- The health sector has a responsibility to champion this, and to ensure that health systems are able to engage and respond to the growing burden of chronic diseases. Health services must also be engaged to prevent, diagnose, and treat these diseases through the integration of primary care,

multidisciplinary specialist services, and public health.

- Person- and people-centred care should be supported by a close collaboration between clinical care and public health. Each person with a chronic disease should be fully engaged in partnership to achieve joint understanding and joint decision making to prevent and treat such diseases.
- Health professional organizations must work with their members to advance person-centered health promotion and care. It should also ensure the integration of health and social services.
- Person-centered public education, professional training and health research are crucial to support effectively clinical care and public health actions for chronic diseases.
- Last but not least, civil society in general must be engaged in efforts to tackle chronic diseases, as the effectiveness of these efforts will largely rest on the commitment of every person and component of society involved”.

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SECTION III

INTERVENTIONS

EARLY INTERVENTION IN SCHIZOPHRENIA

Prof Patrick McGorry, MD, PhD

The last few decades have seen a paradigm shift in the way we think about serious mental illness, and particularly schizophrenia. Until quite recently, schizophrenia was considered as an illness with an almost inevitably poor prognosis, with little hope of doing more than managing the symptoms with medication. However, research over the last two decades has shown that this bleak outlook is by no means justified, and that early and appropriate intervention can change the course of illnesses like schizophrenia.

One of the main reasons why schizophrenia has been considered as such a devastating illness is the fact that it usually first appears during the late teens or early twenties, at a time of life when the young person is finishing their education or entering the workforce, establishing their social network, exploring romantic relationships, and beginning to assume their independence as a young adult. Any serious illness can severely disrupt this normal developmental trajectory, and it is this disruption to a young person's normal development, rather than the symptoms of the illness alone, that impacts the young person so severely. Studies have shown that schizophrenia rarely appears suddenly, and usually has its onset after a long period of increasingly severe symptoms and disability. Indeed, much of the disability associated with the psychotic illnesses such as schizophrenia develops in the few years before the first episode of illness.

Although the idea that it might be possible to modify the course of schizophrenia by treating people early, before the disability associated with the onset of their illness became entrenched, was proposed at the beginning of the last century, research into the early stages of the illness did not begin seriously until the 1990s, when the first studies of

early intervention in psychosis showed that early and appropriate treatment led to better outcomes for young people over the medium to longer term. This work led to the discovery that the duration of untreated illness is the most important factor associated with long-term outcome that can actually be modified by treatment: put simply, early and appropriate treatment allows young people to make a more complete recovery, with less ongoing disability. For the first time, clinicians and researchers were able to show that schizophrenia was not a hopeless illness: it need not be associated with an inevitable decline and ongoing disability.

This work led to a flurry of interest world-wide, and the 'early intervention' movement was born. Early intervention for the serious mental illnesses, like schizophrenia, aims to prevent the onset of illness, and failing that, to minimise the symptoms and distress associated with the illness, and to maximise the chances of the best possible recovery without ongoing disability. Practically speaking, preventing the onset of a serious mental illness means firstly determining who is at risk of developing the illness, and then how to intervene to prevent the illness. As yet, we are not able to do this for schizophrenia, because we do not understand the biology of the illness well enough at present. Much more research is needed to enable clinicians to develop diagnostic tests that are accurate and specific enough. However, the research effort to date has allowed clinicians to identify criteria that indicate that a young person is at greater risk of developing a serious mental illness. These include being aged between 14 to 29 years, because this is when most serious mental illnesses first appear; and seeking help for distressing symptoms such as depression, anxiety and low-level psychotic symptoms.

Recognising that this group of young people is at ultra-high risk of developing a serious mental illness has allowed clinicians and researchers to develop a number of treatment approaches that are

aimed at relieving their symptoms and distress, pre-empting the development of ongoing disability, and preventing the onset of more serious illness. These treatments are tailored to the stage of the young person's illness, and at this very early stage are most likely to include counselling, education and supportive monitoring. If symptoms persist or worsen, cognitive behavioural therapy may be offered, and antidepressant or anti-anxiety medications trialled. Low-dose antipsychotic medication has also been tested in this patient group, but is not recommended as a first line of treatment due to the greater risk of side-effects. Early intervention is particularly important for these vulnerable young people, because although many of them will not go on to develop schizophrenia, their mood and anxiety symptoms have the potential to evolve into more established illness if they are not treated effectively right from the start.

For those young people who do have a first episode of psychosis, early intervention means recognising the illness quickly, and beginning appropriate treatment as early as possible. Initial treatment involves low-dose antipsychotic medication to manage symptoms and distress. However, recovery involves more than just eliminating symptoms; for a young person with a serious mental illness, it also means maintaining or regaining their normal developmental pathway—getting back to work or school, enjoying their social life again, and living a full and meaningful life while moving on into independent adulthood. Hence, early intervention for these young people also means surrounding them and their families with a comprehensive, integrated continuing care system for the first 2–5 critical years after the onset of illness, when the risk of accumulating ongoing disability is highest.

Integrated care involves a small continuing case management team providing medication and psychological treatments to help the young person manage their symptoms and illness, complemented

by a suite of interventions with a strong focus on promoting social, educational and vocational recovery, preferably within a specialist early psychosis service. These services offer a developmentally appropriate, youth-friendly, and inclusive environment where young people can be supported in their recovery by a multidisciplinary team with specialist medical, psychosocial, vocational and educational expertise and a particular interest in youth mental health.

These treatment approaches have been shown to be very effective for young people in the early stages of illness, and are highly valued by both young people and their families. They are also cost-effective, and our growing recognition of the importance of young people's mental health issues, together with popular demand for mental health services that recognise young people's unique mental health care needs, have led to service reforms and new service development in countries like Australia, Ireland, England, Denmark, Canada, and most recently the United States. For example, in 2006 the Australian Federal Government established headspace, a

national enhanced primary care youth mental health system now operating in 70 sites across the nation, with a further 30 centres to be set up by 2016. Nine of these centres are to offer specialised early psychosis care, modelled on our Early Psychosis Prevention and Intervention Centre (EPPIC), in Melbourne.

Young people from many Australian communities are gaining free access to early intervention and evidence-informed, stigma-free care for mental health issues, and they and their families are voting with their feet, with the demand for these services growing steadily. Although it is still too early to assess the long-term outcomes from these service reforms, early indications are very positive. These approaches, which offer holistic care from the outset, contrast with the currently accepted status quo, which all too often and for various reasons, involves outright neglect. Many researchers and clinicians working in this field feel in common with the general public that they have watched long enough, and that young people and their families deserve active engagement and evidence-informed care that is proportionate to their needs.

Approaches like these have already shifted our thinking in mental health care, from what has traditionally been a palliative approach, to a pre-emptive approach that offers the potential for better outcomes for young people, their families, and our society as a whole.

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PSYCHOLOGICAL INTERVENTIONS IN SCHIZOPHRENIA

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Key Messages:

- Psychological treatments are important in helping people with a diagnosis of schizophrenia and their families.
- Cognitive behavioral therapy for psychosis is effective and based on the assumption that the person's own experiences should be taken seriously and that they can be helped to take greater control of their thinking and behaviour.
- Families are often on the front lines of care for persons with schizophrenia.
- Family psychoeducation (or Family Intervention) is effective in the treatment of schizophrenia. Some people particularly value group formats that aim to decrease social isolation and stigmatization.

Psychological treatments are important in helping people with a diagnosis of schizophrenia and their families. Coping with troublesome beliefs and upsetting unusual experiences can be difficult when others don't believe the person. Talking about them with a skilled mental health worker often helps. Psychological treatment is a general term used to describe meeting with a therapist to talk about feelings and thoughts and how this affects a person's life and wellbeing.

Cognitive Behavioural Therapy and Arts Therapies

Cognitive behavioural therapy for psychosis is a form of psychological treatment for which there is large body of research evidence showing that it can be helpful^{1,2,3}. The evidence suggests that about one half to two thirds of people who have this type of therapy show benefits. The therapy involves meeting with a therapist on a one-to-one basis for at least 16 sessions, over the course of 6-12 months. It will focus on the problems which are identified by the service user as important, which might include, for example, feeling anxious and avoiding situations, low mood and inactivity, sleep problems, worry, coping with voices, dealing with paranoid concerns or traumatic experiences, or managing stresses which lead to relapse. The primary goal

is chosen by the person, and often is to reduce the distress associated with psychotic symptoms, such as voices and worrying beliefs (paranoid ideas and delusions), and to work together to get back on the road to recovery⁴. The sessions may involve talking about how problems started, discussing what has happened to the person and how they have interpreted it, understanding the unusual experiences they have, and exploring new ways of thinking and acting when problems occur. For some people, it may help to keep a diary of these thoughts, identify particular patterns in problems, find out more about their beliefs, and how they might be affecting them, and test out if trying to do something new makes them better or worse. The therapy is based on the assumption that the person's own experiences should be taken seriously and that they can be helped to take control of their thinking and behavior.

The research has also found that arts therapies, which do not involve so much talking but make structured use of music, drama or art as therapy, can be helpful, particularly when people have symptoms such as withdrawing from family and friends and losing interest in things that were once enjoyable². These therapies should usually take place in groups with people with similar problems.

The Role of Families and Family Therapy

Families are often on the front lines of care for persons with schizophrenia. The role of a long-term caregiver is accompanied by many burdens and needs for family members, which can leave them emotionally depleted and desperate for help. Family members need support to best assist their ill family member and cope with the stress associated with schizophrenia.

The well-being and clinical outcome of a person with schizophrenia can be significantly affected by the behaviours of family members. This does not mean that families cause the illness, which was an unfortunate misperception that originated in early work with families⁵. However, particular family variables strongly influence recovery from schizophrenia. Expressed emotion (EE), which includes criticism, hostility, and over involvement, has been shown to be a strong predictor of outcome in schizophrenia. When families of patients with schizophrenia have high EE, there are more frequent relapses in comparison to families that have lower EE⁶. Engaging families in treatment

allows the mental health worker to address relational stress that may exacerbate problems, support families in their care of mentally ill person, and access a family's skills and resources to help the patient in need.

Family psychoeducation (FPE), also called Family Intervention in some countries², has been shown to be effective in the treatment of schizophrenia and is now deemed an evidence-based practice for reducing relapse and hospitalisations⁷. FPE is a collection of programs aimed at providing information about the illness, medication management, and treatment planning to family members as they cope with their family member's symptoms and the effects of illness on the family⁸. These programs assume that 1) the actions of family members impact the person coping with illness and his treatment and 2) family members need information and support in caring for a family member with severe mental illness. FPE is increasingly offered in a group format, where families join together to decrease social isolation and stigmatization and reap the benefits of mutual support⁷.

Below are examples of interventions in FPE⁹:

- Assess the family's strengths and limitations in their ability to support the patient
- Help resolve family conflict through sensitive response to emotional distress
- Address feelings of loss
- Provide an explicit crisis plan and professional response
- Help improve communication among family members
- Encourage the family to expand their social support networks
- Be flexible in meeting the needs of the family
- Although international research supports the use of these psychological treatments, it is important to note that treatments can take many forms. They need to be tailored to meet the person's and family's circumstances and culture. Staff, therefore, need specialized training and skills to undertake this work, with regular support and supervision.

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COMPUTER-ASSISTED THERAPY FOR PERSECUTORY VOICES UNRESPONSIVE TO MEDICATION: AN EFFECTIVE SOLUTION

Professor Julian Leff

The introduction of anti-psychotic medication in the 1950s led to a great improvement in the treatment of psychotic illnesses. However not all patients responded to this treatment. In particular one in four patients who hear voices abusing them and /or giving them commands to harm themselves or others are not helped by medication. Their quality of life is greatly impaired by these persistent experiences, which interfere with thinking, working and socialising. Sadly one in ten patients who are plagued by these voices commits suicide. The development of cognitive behaviour therapy for psychosis by British psychologists has been shown to reduce the stress caused by the voices, but does little to influence the volume or frequency of the voices.

When patients with these symptoms are asked about the worst aspect of their experience, most of them reply that it is the helplessness. However a small number are able to establish a dialogue with the voices, which gives them a stronger feeling of control. The difficulty of attempting to interact verbally with the voices is their invisibility. In everyday life we depend heavily on the responses of the other person to maintain a conversation, including eye contact, smiling and nodding the head. Of course none of these are available from the voices. Furthermore what the voices say are usually brief repetitive phrases, such as 'punch yourself in the face', which are unrelated to what the patient is saying to them. It seemed to me that if it was possible to give the invisible voice a human face which was responsive to the patient they might be better able to establish a dialogue.

In thinking about this possibility it occurred to me that an avatar would be a solution. Avatars are computer generated images that are now universally used in computer games, with which even young children are familiar. What I needed was something more specialised, namely an avatar that the patient could create, with a face that they believed belonged to the voice, and a voice that approximated to the one that was persecuting them. I worked with two speech scientists, Mark Huckvale and Geoffrey Williams, who developed a computerised system that would achieve

this. It was crucial that the therapist could control what the avatar said in order that its persecutory abuse could be modified. This was achieved by recording the voice of the therapist (myself) reading a number of short paragraphs, and then Mark Huckvale changed various characteristics of the recordings to provide a series of varied voices from which the patient could select the one most similar to their persecutor. It was then possible for the therapist to speak to the patient with the chosen voice and to decide what the voice would say in response to the patient.

The patient was shown a variety of faces, which could be modified in a number of ways, hair and eye colour, shape of nose, breadth of face, from which the patient could construct a face which represented their persecutor. Some patients knew the individual whose voice they heard, while others did not associate an identifiable person with the voice. These patients were asked to choose a face which they felt comfortable talking to, and that was acceptable to them.

The therapy consisted of 6 sessions of up to 30 minutes each. Before the first session the patient was asked what the voice usually said. The therapist wrote this down and spoke it in the first session in the voice chosen by the patient, who was warned that this would happen, and was reassured that the therapist would support them against the avatar. This was possible because the therapist, who was sitting in a room some distance from the room occupied by the patient, had a separate screen which allowed him to choose either to speak in the changed voice as the avatar or in his natural voice as the therapist. So the therapist was playing two roles in sequence: either as the persecutory avatar or as the supportive therapist. The patient was unaware of this and all but two of the 16 patients who received the therapy accepted the avatar without question as the voice they heard.

In the course of the 6 sessions of therapy, the therapist progressively changed the character of the avatar, altering its relationship with the patient in that it gradually stopped its abuse and allowed the patient to take control of it. Eventually the avatar acknowledged the good qualities of the patient and offered advice on how the patient could improve her/his life. For example one patient who complained of loneliness was asked if he had any hobby. The patient replied that he had

always been interested in sailing but had never experienced this activity. The avatar responded by suggesting that he join a sailing club, and the patient agreed that this was a good idea.

Every session was audiotaped and the recording was transferred to an MP3 player which was given to each patient to keep. They were encouraged to listen to the sessions whenever they were bothered by the voice or when they felt miserable. They were told that they now had a therapist in their pocket!

The effect of the therapy was assessed by a scientific trial with random allocation of the patients to avatar therapy or to their usual treatment, which consisted of antipsychotic medication and regular supervision by their psychiatrist. The results were far better than expected. A majority of patients experienced the voice or voices becoming quieter, less frequent and also less abusive. The patients felt they had much more control over the voices. One of them remarked that the voices spoke much less to her because they knew she would answer back. There was also a reduction in the patients' depression and in suicidal thoughts. The most dramatic and completely unexpected effect was that three patients ceased to hear their persecutory voice altogether: two of them experienced this relief after only two sessions of the therapy and one after five sessions. They had been hearing the voices for sixteen years, thirteen years and three and a half years respectively.

It needs to be stated that by no means all of the patents had such good outcomes. Two patients heard multiple voices that spoke so loudly that they could not concentrate on the avatar. Others were threatened by their voice with harm to them or their relatives if they proceeded with the therapy. Avatar therapy therefore is not suitable for all voice-hearers. However the results of the trial were impressive enough to justify a much larger study, and this has now been funded and is well under way. It is planned to take three years to complete. If it successfully replicates the findings of the first trial a major effort will be made to develop a portable version of the computerised system to make it available to all who could benefit from it.

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CO-MORBIDITY AND SCHIZOPHRENIA: PHYSICAL HEALTH IN PEOPLE WITH SCHIZOPHRENIA – THE FACTS

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There is now increased awareness amongst psychiatrists and other health professionals that people with schizophrenia suffer from an increased risk of morbidity and mortality compared to the general population. Unaddressed physical illnesses in this population can lead to a reduced life expectancy of up to 20 years. Two thirds of the premature deaths in this population are due to physical illnesses, with cardiovascular disease (CVD) being the major contributor. Those suffering from schizophrenia are twice as likely to die from CVD as those in the general population.

Several modifiable risk factors contribute to the increased risk of CVD in this population. Of note, the total risk is significantly greater than the sum of the individual risk factors added together, suggesting an accumulative effect. As a result there has been an increasing concern about physical health in people with schizophrenia, specifically CVD. People with schizophrenia are also more likely to be overweight, smoke, and have diabetes, hypertension and dyslipidaemia (abnormal fats). This cluster of risk factors, including impaired glucose tolerance, central obesity, hypertension and dyslipidaemia, has been described as metabolic syndrome.

The incidence of metabolic syndrome in people with severe mental illnesses is 2-3 times greater than the general population. The surrogate marker for

metabolic syndrome is central obesity, easily measured by waist circumference, along with abnormalities in 2 of the following parameters; low HDL (high density lipoprotein) cholesterol level, elevated triglyceride, high blood pressure and elevated blood glucose. (Metabolic syndrome IDF definition 2005)

Whilst cardiovascular and metabolic diseases occur more commonly in people with schizophrenia than the general population, other physical health problems such as infections, neoplasm and medical complications of alcohol and drug misuse are also more frequent and have a greater impact on individuals with schizophrenia. Therefore it is essential to recognise physical illnesses early on and treat them without delay.

Sources of risk associated with physical health problems

Although many risk factors, modifiable and non-modifiable, contribute to the poor physical health of people with schizophrenia, the increased mortality is largely due to the modifiable risk factors - many of which are related to lifestyle choices which we can alter.

Risk factors which are non-modifiable include your genetics, age and gender. There is growing evidence that there may be a genetic link between schizophrenia and the development of physical health problems such as glucose intolerance leading to diabetes.

Modifiable risk factors are those factors which we can influence to improve physical health in this population.

It is now established that those with mental health problems do not receive equal access to medical services, due to poor provision of services to conduct health checks, stigmatisation, and lack of awareness and education of family doctors.

A Patient perspective

"It seems that once you have a mental health diagnosis any physical symptoms you experience are instantly assumed to be part of your diagnosis. Once that assumption is made it is difficult to get anyone to attempt to disprove it." Rethink anonymous mental illness person comment" (2013)

In addition, people with schizophrenia are less likely to seek medical treatment for physical illnesses, which can delay making a diagnosis and getting treatment for many years. This can lead to a poor prognosis and ultimately reduced life expectancy.

It is commonly known that people with the illness are more likely to eat diets high in saturated fats and refined sugar but low in fibre and little in the way of fruits and vegetables.

Exercise and physical activity are more limited due to lack of mental wellbeing, poor motivation/drive, lack of structure to life, and at times lack of prioritising financial resources.

They are more likely to smoke excessively and misuse alcohol and drugs, resulting in worse mental, physical and social outcomes, with increased relapse rates, homelessness, unemployment, family breakdown and criminality.

The mainstay of treatment for people with schizophrenia is antipsychotic medication. There is now a greater choice of medication for the treatment of the illness. The second generation of antipsychotics, called the 'atypicals', provides more effective treatment options, with a reduction in movement disorders. The aim is to optimise mental and physical wellbeing, but some of these medications have an increased risk of cardiovascular and metabolic problems including coronary artery disease, weight gain, lipid abnormalities and Type II Diabetes.

Measurements for monitoring physical health in SMI patients with baseline values

	Baseline	6 weeks	3 months	At least at 12 months and annually thereafter
Personal and family history	X			
Smoking, exercise, dietary habits	X	X	X	X
Weight	X	X	X	X
Waist circumference	X	X	X	X
Blood pressure	X	X	X	X
Fasting plasma glucose	X	X ¹	X	X
Fasting lipid profile	X	X ¹	X	X
ECG parameters	X			
Prolactin	X ²		X ³	X ³
Dental health	X			X

¹ This early blood sugar and lipids assessment has been recommended in Europe, but not in the US

² If possible to have some reference values, or, if this is too expensive, only in case sexual or reproductive system abnormalities are reported

³ Only in case of sexual dysfunction that coincided with antipsychotic treatment or dose change

How do we work together to improve physical health in people with schizophrenia?

The good news is that health care professionals, people with schizophrenia and carers/families are now much more aware of the risk of physical health problems in people with this illness. We are now in a better position to provide education and support in the form of health checks and lifestyle management. As a consequence individuals with schizophrenia will be more informed and have the opportunity to engage with lifestyle programmes enabling them to take more responsibility and make decisions about their own physical wellbeing.

Care of people with schizophrenia must be person-centered and collaborative, taking into account the patient's needs and preferences so that they can make informed decisions about their physical and mental wellbeing. Through effective communication, providing evidence-based information and adopting a proactive approach, there is no reason why people with schizophrenia cannot live long and healthy lives.

Health checks for people with schizophrenia are essential to monitor cardiovascular and metabolic risk factors along with general health screening. The World Psychiatric Association recommends the checks listed in the following chart.

Lifestyle management for prevention of physical health problems

Simple tips regarding changes in lifestyle can have a dramatic effect on long term outcomes and life expectancy.

Cardio-protective Diet

- Cut down on fatty foods
- Increase fish intake
- Increase fruit and vegetables - five portions /day
- Decrease processed food,
- Minimise sugar/sugary drinks

Tip: Be more aware of healthy foods, learn to cook, go healthy food shopping.

Physical Activity

- 30 minutes of moderate exercise at least 5 days per week- a brisk walk for 30 minutes, 5 days/week.
- Change lifestyle to incorporate exercise - walking, using stairs, cycling
- Agree goals and provide written evidence about the benefits

Tip: It is not essential to join a gym but changing lifelong bad habits can make a dramatic difference - be more physically active!

Weight Management

- Offer advice on weight management and how to achieve a healthy weight and maintain it

Tip: set realistic targets for weight reduction and then maintain weight

Alcohol Consumption

- Advise men 3-4 units per day limit (no more than 21 units per week)
- Women 1- 2 units per day (no more than 14 units per week)

Tip: Avoid binge drinking - stick to the recommended units!

Smoking Cessation

- Advise all people to stop smoking
- Offer support and advice: include pharmacotherapy and smoking cessation

Tip: the best advice - stop!

Sexual Health

- Sexual health education to reduce high risk practices leading to sexually transmitted diseases.

Tip: use safe practices at all times.

Regular medication reviews and switching if necessary

It is essential when people with schizophrenia are treated with antipsychotic medication that there is regular monitoring of medication.

Psychiatrists have a specialist role in initiating antipsychotic medication, monitoring potential adverse effects and offering advice on switching medication to a different 'lower risk' medication where and when necessary. It is essential that psychiatrists work collaboratively with the family doctor, the patient, and the family/care giver to improve understanding of the prescribed medication and how potential adverse

effects can be minimised. It is important to choose a medication that gets the best risk/benefit and meets the patient's needs.

Medication choices need to be fully discussed before initiation, working collaboratively with the patient and his/her carer. The individual should be engaged in the decision making process regarding the medication or any switching. It is important that a switch to an alternative lower risk medication is considered when there are risk factors such as obesity or diabetes. When a switch is considered all aspects of the patient's mental and physical wellbeing must be considered carefully and discussed openly with the individual and the carer/family member.

Conclusions

There are still major challenges for health care professionals to work with people with schizophrenia to improve their physical health outcomes and manage co-morbidity effectively. A person-centered integrative model with psychoeducation empowers patients to make informed decisions about their treatment plan and lifestyle management. This enables the patient and the family to play a significant role in the treatment and monitoring of physical health.

The WFMH International Keeping Care Complete survey demonstrated the importance caregivers placed on overall wellness, with 99% saying the goal of treatment should be to maintain wellness defined as the condition of both physical and mental health.

Although there is an increased awareness in this area, more education is required for health care professionals, patients and carers/families to improve outcomes and increase life expectancy. By adopting a person-centered approach there is an opportunity to improve the overall physical and mental wellbeing of people with schizophrenia. Simple lifestyle changes with regular health checks and review of medications can optimise treatment and improve the overall quality of life for people with schizophrenia.

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THE IMPORTANCE OF CARERS IN SUCCESSFULLY LIVING WITH SCHIZOPHRENIA

"Mental health services have a duty to carers in recognising the valuable role they play and in ensuring they are aware of the support available to them. This is not just in terms of practical support, but also emotional support which can make a huge difference to a carer's own health and wellbeing." Stephen Dalton, chief executive of the NHS Confederation's Mental Health Network in the UK (ImROC, 2013)

Schizophrenia is a chronic, disabling mental illness that affects a person's ability to think clearly, manage emotions, make decisions, relate to others and identify what is real. Schizophrenia affects approximately 24 million people worldwide, mainly people aged 15–35 (WHO, 2011) and the World Health Organization has ranked it among the top-10 leading causes of years lost to disability (WHO, 2004). Because the onset of schizophrenia occurs in late adolescence or early adulthood, the illness has a devastating impact on a person's education, job opportunities and on their capacity to have a family or a social life (Bevan, 2013; Lieberman, 2001). Nevertheless, with the right medication, a tailored plan of care and support services, most people with schizophrenia can cope with their symptoms, maximise their functioning and minimise their relapses (Duckworth, 2011).

In recent decades, there has been a fundamental change in the way that people with mental illness are cared for. Community-based care and prevention is now preferred over long-term hospitalisation, and the responsibility for care has shifted from hospitals to informal carers, such as a relative (Schulze and Rossler, 2005). Family members are the likely primary carers of people with schizophrenia. A survey of 982 carers, conducted by the World Federation for Mental Health in Australia, Canada, Germany, France, Italy, Spain, the United Kingdom and the United States between November 2005 and June 2006, revealed that carers can spend more than 10 hours per week caring for their relative (WFMH, 2013). Often carers will give up their job or take time off work to provide care and support for a family member (Mangalore and Knapp, 2007). Caring

for someone with schizophrenia takes time, energy, financial and emotional resources (MacCourt, 2013). In addition to activities of daily life, carers often monitor symptoms, manage problematic behaviours, situations and crises, provide companionship, as well as emotional and financial support (MacCourt, 2013). Unfortunately, carers report higher levels of burden, distress, stress, anxiety, depression and lower levels of life satisfaction (MacCourt, 2013; Schulze and Rossler, 2005).

Carers fulfil a distinct and important role by providing support and advocating for their ill relatives as well as contributing to their recovery (MacCourt, 2013). Therefore, it is important to educate, support and ease the burden of those who care for people with schizophrenia (Awad and Voruganti, 2008). Over the years, a number of family interventions have been developed to help people with schizophrenia and their carers to receive education about the disease and training in problem solving (The Royal Society of Medicine Press, 2000). Education improves a carer's knowledge of schizophrenia, but supportive family education goes beyond giving information about mental illness and gives carers the tools to develop strategies to cope with the burden of caring for someone with a mental illness (Macleod, 2011). People with schizophrenia who have participated in family intervention sessions have experienced a reduction in the number of relapses as well as in the number and the length of psychiatric hospitalisations (Giron, 2010). With the appropriate training and support, carers can identify sources of stress and intervene early on in a crisis situation to prevent major incidents, such as suicide attempts, fights, substance abuse, vagrancy or risky behaviour (Giron, 2010). Family interventions can have a significant impact on negative symptoms and can help people with schizophrenia improve their motivation to engage in social activities and relate to other people as well as provide them with a positive outlook to get a job (Giron, 2010). In this respect, family interventions have a dual effect, first by creating a more stimulating family environment that encourages opportunities for activities that may help reduce negative symptoms, and second by providing an environment that may reduce the intensity of positive symptoms by helping carers identify potential sources

of stress for their relative and help them cope with it (Giron, 2010). In a two-year randomised controlled study, 50 people with schizophrenia were separated into two groups, half of participants received family intervention (intervention group) and half did not (control group). Only 12% of patients in the family intervention group experienced a clinical relapse compared with 40% of patients in the control group. More patients in the intervention group also experienced improvements in functioning compared with the control group (56% vs 28%, respectively). Interestingly, no patients in the family intervention group experienced a major incident compared with 32% of patients in the control group (Giron, 2010).

"It is deeply painful for anyone to interact with a loved one whose behaviour is determined by a mysterious internal mechanism that has gone awry. But with support and education, carers can be taught to recognize impending symptoms of relapse and help their loved ones avoid situations that might trigger them." NY Times in-depth health report (A.D.A.M., 2008)

Carers are in a position to intervene early before the symptoms of a potential episode worsen, the situation escalates and the person with schizophrenia needs to be hospitalised (Giron, 2010). Early intervention means providing information, assessment and treatment at the earliest possible time when the person with schizophrenia starts experiencing psychotic symptoms, and the complications that can arise from untreated psychosis take hold (Lieberman, 2001). Despite the essential role that carers have, they are highly exposed and caring for a relative with mental illness is related to high personal suffering, feelings of guilt, helplessness, fear, vulnerability, anxiety and anger (WFMH, 2009). Given that the frequency and intensity of psychotic episodes is unpredictable, coping with such a condition poses ongoing challenges to family carers (MacCourt, 2013). Most family carers would benefit from receiving information, education, guidance and support (MacCourt, 2013). When asked about what would most support them in their role, carers reported that they needed (MacCourt, 2013):

- To know that the person they care for was receiving adequate care and services, and that their loved one was able to achieve a reasonable quality of life
- To have their relationships and role as carers recognized by mental health service providers and to be meaningfully involved in assessment and treatment planning
- To receive information, skills, support and services from knowledgeable mental health service providers to enable them to effectively provide care to the person living with a mental illness
- To receive support and services for the family and its individual members to sustain their health

The needs and challenges that carers face will change as the illness of their relative progresses, but it will also depend on the individual characteristics of the carer, their social networks and personal resources (MacCourt, 2013). Therefore, timely and adequate support for carers will not just benefit the carer but also the person living with schizophrenia as the health and well-being of carers will have a direct effect on the person living with the disease.

Schizophrenia is a disabling mental illness that affects the life of both the people affected by it and those who care for them. Carers fulfil the indispensable role of providing support and advocating for those with mental illness as well as contributing to their recovery. With

appropriate education, training and support, carers can have the tools to develop strategies to cope with the burden of caring for someone with schizophrenia. Timely and adequate support for carers will empower them to intervene early before the symptoms of a potential episode worsen and the situation escalates, and thus improving the quality of life of those in their care.

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HERE IS SOME ADVICE FOR HELPING A PERSON WITH SCHIZOPHRENIA

eHealthMD

- Remember that schizophrenia is a medical illness. Do not feel ashamed because someone in your family has it.
- Do not feel guilty or seek someone to blame. Schizophrenia is nobody's fault. Acceptance is important.
- Educate yourself about your relative's personal symptoms. Early clues, such as changes in sleep patterns or social withdrawal, can indicate that a relapse may be happening.
- Establish a daily routine for the person to follow.
- Help the person stay on the medication.
- Let the person know that he or she is not facing the illness alone. Keep lines of communication open.

- Try not to show overt anxiety or distress. Avoid harsh or direct criticism.
- Compliment on achieved goals without being effusive in your praise.
- Realize that caring for the person can be emotionally and physically exhausting. Take time for yourself.
- If the person can no longer be cared for at home, speak with the doctor about alternatives for care.

Read more: <http://ehealthmd.com/content/how-can-family-help#ixzz33VihVuE>

SECTION IV

RECOVERY IS POSSIBLE

FINDING RECOVERY WITH SCHIZOPHRENIA

Janet Paleo

Schizophrenia. Even the mention of the word can send a shudder through a person, a wave of fear through a crowd, or alienation in a community. When the word is being said about you, there is a shock of disbelief, anger and fear. I know. I was diagnosed with schizophrenia.

This was not a good time in my life. I was hospitalized with severe acute major depression and while still in the hospital a year later that diagnosis was changed to the big S (schizophrenia). All in all, I have had nine different diagnoses. The big S scared me the most.

I had heard about people with schizophrenia. They were nothing short of uncontrollable monsters and now I was one of them. I always tried to be a good girl. I never told the secrets when I was young. I never hurt other people even if they were hurting me. I had met a lot of monsters and I never thought that would include me.

I sank into despair and that is all I could see in my world which almost left me comatose. At the same time my insurance ran out, my daughter went from living with friends to being in a foster care system and my job, which had been held for me, closed. The house I had been paying my share of the rent on was no longer available as my roommates decided they didn't want to live there anymore.

My world turned chaotic. Voices filled my head. Shadows of people haunted me and only I could see them. Bugs crawled on my skin and I could not see them. I remember withdrawing into a fantasy world where I couldn't hear or see anyone. I was lost in a world and wandered aimlessly in my mind only wanting life to stop.

I tell you this, not to scare you but to have you understand my experience. Doctors gave up on me and so did most family

and friends. This is what the big S felt like from inside of me. There was no hope, no future and no reason to even breathe. Most of all, I wondered why God hated me so much.

Back then, I never heard the word 'recovery' or anything about getting better. I was in a psych hospital for two years. I lied to get out. I got my daughter and retreated to my home state and began a multi-year process of trying to hide from everyone and everything. During this time I easily had over 50 hospitalizations. I hated life and everything about life. There was one thing I hated more than life and that was me.

A psych tech once asked me to describe the pain in me. Where was it located? How did it feel? How could I ever express to anyone this overwhelming, piercing agony that lived within me? There was no relief, no respite; no escape except for the retreat within my head. Some called it psychosis, I called it relief.

Through a series of events that offered my first glimpse of hope, I finally found the road to recovery. To be sure it was a long road full of potholes and at times I had to go backwards to go forwards. I found tools and skills to neutralize my past. Nothing could make me forget, but the power those memories had over me disappeared. I found a purpose in life. I realized what strength I had to survive the life I had been given. I also realized that God had not forsaken me, but was preparing me for the life I have now. I had to go through all of that misery to become the person I am today. Like a diamond, I was put under extreme pressure for an extended period of time, and emerged a hard crystal that can shine brilliantly.

It was not the medication I was given, and there was a lot. It was not the therapy I was given, and there was a lot of that as well. It was a person who had gone through her own version of hell who had an understanding of what it was

like to be me. My road to recovery really began with that human connection and understanding. Recovery was learning from others who had experienced schizophrenia and gone on to have a life worth living. Recovery was people seeing the potential in me and investing in me. Recovery was beginning to see hope and a future. When we start focusing on those elements, I believe we can make a significant difference in the world. Recovery is possible. I know. I am the proof.

Today my life is full, rich with hope and dreams. I work full time for the Texas Council of Community Centers as the Director of Recovery Based Services. I sit on the Board of the World Federation for Mental Health. I am the founder of Prosumers International and have created a three day resiliency training called Focus for Life along with Anna Gray. I own a home in San Antonio and keep an apartment in Austin. I travel around the world, often as an invited speaker. At the age of 57 I swam with the dolphins. I am an instructor in Mental Health First Aid and in Intentional Peer Support. I sit on state policy committees and testify before legislators. I am busier than people half my age. I love my life. More importantly, I finally love me. I no longer need to protect myself from the pain. When I say recovery, I mean having a life worth living.

The time has come for us to make recovery available to everyone. Everyone deserves that chance.

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THE IMPORTANCE OF HOLISTIC CARE FOR PEOPLE LIVING WITH SCHIZOPHRENIA

Gabriel Ibvijaro, Sir David Goldberg, Henk Parmentier, Lucja Kolkiewicz, Michelle Riba, Richard Fradgley and Anwar Ali Khan

World Mental Health Day 2014 on the theme Living with Schizophrenia provides an opportunity to reflect on what we as individuals and families are doing, and will continue to do, for people living with schizophrenia—and also to reflect on what organizations and government departments are doing.

For too long, and perhaps because of a lack of understanding, receiving a diagnosis of schizophrenia tended to suggest an inevitable deterioration.^{1,2} Even early longitudinal studies³ showed that this view was too pessimistic, since studies in the pre-neuroleptic era showed a good outcome in one third of cases, although with “profound deterioration” in 46% of Swedish patients admitted in 1925. Studies since the neuroleptics became available are considerably better, with complete recovery varying between 17% and 35% in various longitudinal studies. In the WHO international study of schizophrenia, although outcome in developed countries was comparable to these rates (36.8%), that in developing countries was much higher (62.7%)⁴. In a follow up study of people with psychotic illness in 14 countries, 25 years after onset of the disorder 48.1% of those initially diagnosed with schizophrenia and 56.2% of those initially diagnosed as having “other psychoses” were rated as recovered, while 42.8% of those with schizophrenia and 49.5% of those with “other psychoses” had not been psychotic over the past 2 years⁵.

This story needs to be told in order to provide hope to the people who are living with schizophrenia, and their families and friends. It provides an opportunity to continue to tackle the stigma and the lack of dignity associated with the wrongly held belief that schizophrenia results in inevitable deterioration.

From the 1950s on there followed a period of de-institutionisation, where major emphasis was placed on various forms of rehabilitation, most notably industrial forms, but also including agricultural exposure and other forms of vocational experience, all aimed at

enabling a person with schizophrenia to function in society. The need to find places in the community for patients to live led to a wide range of accommodation being made available, and that has undoubtedly normalised the experience of living with schizophrenia. The introduction of the Care Programme Approach in the 1980s in the UK, for example, led to individual care plans being made for patients, with routine care in the community being provided by a community psychiatric nurse (CPN). Finally, the progressive reduction in the number of in-patient beds in the UK has led to the steady decrease in the average length of stay, with increasing use of the “revolving door” of in-patient units. Schizophrenic patients living in the community are registered in the UK with a general practitioner (GP), and this has led to an improvement in the clinical skills of GPs themselves. A modern community-based mental illness service no longer sees the severely deteriorated cases that were seen during the asylum era, and both community-oriented services and modern drug treatment may be responsible for the better outcomes now reported.

Despite these undoubted improvements, the WHO mhGAP Programme showed that many people with schizophrenia globally have little or no access to health care and have poor outcomes.⁶ Surprisingly this is not limited to middle- or low-income countries. Surveys show that up to 40% of people diagnosed with schizophrenia in the USA have not received mental a health intervention⁷. Recovery will not be possible without enhancing access to and improving the quality of services that people receive.

There have been global improvements in health and health outcomes, and people are living longer in high-, middle- and low-income countries. Unfortunately for those people with mental health problems, especially schizophrenia, life expectancy can be up to 20 years less than the rest of the population. This is unacceptable and should not be allowed to continue⁸. There is therefore a need for further improvements in arrangements that are made for the care of people with long-term schizophrenia.

Holistic Care of Schizophrenia

The holistic concept in medical practice maintains that all aspects of people's

needs, including psychological, physical and social, should be taken into account and seen as a whole. The mental health consumer movement has also been a force that places emphasis on a more positive view of the outlook, and more holistic care may hold the key to still further improvements. The term goes well beyond the usual medical model of services provided either by specialist mental health teams or by primary care, and should cover care provided by others such as housing support workers, informal carers and others such as neighbours and concerned family members.

Since recovery is possible we need to adopt a holistic approach to care that will address the social determinants of mental ill health, including poverty, housing and living conditions, nutrition, education, employment, unsafe social and community networks, empowerment of women and support for the parenting role, access to immunisation programmes and universal access to primary health care facilities integrated with other social and health care systems.⁹

There have been many initiatives to advocate for and promote health values, including the recent UN Millennium Goals programme¹⁰. Unfortunately, many people with schizophrenia have not enjoyed these universal benefits. In England, only 5-15% of people with schizophrenia are in employment and, when you consider that schizophrenia is an illness of young people, this statistic illustrates that many people with schizophrenia are trapped in a net of poverty which makes them unable to move on in their lives. Supporting people into, or back into, employment is an important goal for health intervention and health promotion programmes, and also starts to address the stigma surrounding mental ill health and promotes recovery¹¹.

How can we promote further recovery and holistic care?

The concept of psychosocial rehabilitation has led to the introduction of client choice, and appreciation of strengths and empowerment. There was a recognition that in the aftermath of the acute illness there was a need to place an emphasis on regaining everyday skills, including use of public transport, self-maintenance, vocational skills and social interaction skills. This sowed the seeds for the

consumer movement that led to the concept of recovery^{12, 13, 14}.

Consumers, service users, patients and their loved ones have moved the idea of recovery forward to clearly articulate what recovery should look like. In many countries the recovery movement has provided a framework for intervention, support and preventive services. A good working definition was agreed during a 2004 meeting convened by the Center for Mental Health Services of the US Substance Abuse and Mental Health Services Administration, where it was stated that:

Mental health recovery is a journey of healing and transformation enabling a person with a mental health problem to live a meaningful life in a community of his or her own choice whilst striving to achieve his or her full potential.¹⁵ This is a definition that all of us can sign up to, whatever our personal or professional background. Living with schizophrenia and supporting recovery can only happen using a holistic approach and by applying holistic understanding. To unlock everybody's true potential requires good leadership in the context of an anti-stigma campaign to promote social inclusion, early intervention in schizophrenia in the context of strong prevention measures, the provision of evidence based practice and parity of mental and physical health care to address premature mortality.

The WHO Global Mental Health Action Plan 2013-2020¹⁶ provides us all with a new opportunity to put the spotlight back on mental health. We know that there are islands of good practice in all the continents of the world but they need to become the norm, not the exception.

In the United States, the Patient-Centered Medical Home (PCMH) is being promoted as a means to improve access to primary care, enhance delivery of preventive services, better manage chronic diseases, and decrease emergency department visits and hospitalization. While this model will work best in highly integrated medical systems, there are opportunities for all patients, high or low utilizers, to benefit from some of the approaches embedded in the concepts surrounding the PCMH, and thereby providing more holistic patient-centred care. Some approaches for outreach and monitoring will include smart phone technologies, home visits,

and family and caregiver support and education; post-hospital patient care protocols; and enhanced access and tracking of emergency department care¹⁷.

Two examples from East London, UK, provide examples of holistic care in action. The first, a joint collaboration between the London Borough of Tower Hamlets¹⁸ and East London National Health Service Foundation Trust, shows how supported housing can be better used to support recovery and social inclusion for adults with mental ill health. The project began in 2009 when both the Local Authority and the local mental health provider realised that there was a need to improve housing support and procurement for people with long-term mental health problems, particularly those with schizophrenia. A team was set up to promote a whole-systems approach to more effectively manage the accommodation and resettlement needs of adult mental health service users across the range of supported housing options, including registered care and high-, medium- and low-supported accommodation. The team ensured that people with mental health problems were proactively managed to live in accommodation relevant and appropriate to their level of need, with a robustly constructed care plan which had a clear focus on rehabilitation and recovery.

A renewed emphasis was placed on quality and service user experience in registered care and supported accommodation through reviewing care plans when making planning placements underpinned by Individual Placement Contracts. The Local Authority increased the number of mainstream tenancies made available for people with mental health problems to support social inclusion. Value for money was enhanced by using well-developed brokerage expertise to negotiate the price of registered care placements on a case-by-case basis, ensuring that price is based on evidence of service user need and local market cost.

This project has enabled more people with long-term mental health problems to share and enjoy similar aspirations as the rest of us for independent living, recreation, employment, social relationships, material goods and cultural needs. It also provides value for money for those who fund services. In the five years before the project started there

had been a 15% increase in the cost of supported placements for people with mental health problems year on year. This has now been halted whilst improving the quality and range of housing-related support available. The key lesson learned from the project was that, to make real change, health and social care providers need to collaborate so that appropriately supported housing can be commissioned. This has required high level trust between different organisations and senior managers who believe in the project.

The second example, a project from Waltham Forest in East London, began in 2011 with an eighteen-month £150,000 grant from NHS London¹⁹. This primary care project piloted the role of Navigators who are non-doctors and non-nurses trained in understanding the local community resources. They harness the advantages provided by the wider determinants of health for mental health service users with long-term mental health problems, particularly schizophrenia, including the better use of primary and secondary care resources. Their roles include supporting concordance with medication, enhancing engagement with social networks and resources including libraries, sports facilities and volunteering opportunities, and also improving the uptake of health screening programmes by people with mental health problems, while promoting dignity and de-stigmatisation. So far 185 patients from 17 GP primary care practices, supported by four Navigators, have participated in the project and preliminary evaluations are positive. There has been a reduction in hospital re-admissions and increased uptake of social activities, including use of library facilities, re-engagement with employment and education, and increased patient satisfaction.

Waltham Forest is planning to scale up this service in collaboration with other areas of East London. The project will adopt a range of principles to ensure success, including care planning unique to the patient, an integrated approach across primary, secondary and social care, data sharing underpinned by a good IT system, and ensuring that the patient and their family remain at the centre of care. Waltham Forest is happy to share its learning with people who would like to know more about this initiative.

Low- and Middle-Income Countries (LAMIC)

These examples from high-income countries cannot easily be generalised to the rest of the world, where expenditure on mental health is a tiny fraction of that spent in the UK and USA. A 2001 Institute of Medicine report on mental illness in low- and middle-income countries found that in 1990, over two-thirds of people with schizophrenia in these countries were not receiving any treatment²⁰. Patel argues that since there is less than one qualified mental health professional for half a million to a million people, most people with schizophrenia in LAMIC probably receive little or no formal care. Despite these scarce resources, there is now growing evidence that antipsychotic drugs and community-based, family-focused interventions are effective treatments, and the lion's share of the service delivery would need to be the responsibility of non-specialist health workers²¹.

A survey of psychiatrists in nearly 60 countries on the strategies for reducing the treatment gap confirms the need for assistance by both non-specialist providers and the active involvement of people affected by mental disorders²². A pilot study of such an intervention with 256 people with psychotic illnesses showed a significant reduction in the levels of disability for the whole group, the vast majority of whom had engaged with the programme²³. A further example of how such a service can be delivered by a lay health worker (supervised by specialists) in three rural areas in India consisted of 5 components: psycho-education; adherence management; rehabilitation; referral to community agencies; and health promotion²⁴.

More holistic care for schizophrenia is therefore likely to use different tools in different cultures, but all will contain individual care plans for those affected by the disorder, and personal contact with trained carers.

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SECTION V

TIME TO ACT

LIVING A HEALTHY LIFE WITH SCHIZOPHRENIA: PAVING THE ROAD TO RECOVERY

M.T. Yasamy, A. Cross, E. McDaniel, S. Saxena

Background

People with schizophrenia can recover^{1,2}. The service users, their families, communities and the health and social care providers need to recognize such a possibility and maintain realistic hope during treatment^{1,3}. However, for most of the affected population in the real world, especially those with poor psychosocial support, this would be a lengthy and strenuous journey. One extreme for people living with schizophrenia is immediate and complete recovery; the other is enduring disability. The gray zone in between embraces the majority of affected people.

We briefly review the different requirements for a better outcome among people with schizophrenia, as well as how certain changes and interventions can contribute to the healthy life that is attainable for people living with schizophrenia. A “healthy life” here refers to the WHO definition of health which comprises physical, mental and social health. Respecting the human rights of people with schizophrenia is an overarching principle that needs to be recognized across all these interrelated aspects of health.

Physical Health

Premature mortality

An important phenomenon observed among people with schizophrenia and other severe mental disorders is poor physical health and premature death. Such physical health disparities have rightfully been stated as contravening international conventions for the ‘right to health’^{4,5}. The physical health of people with severe mental illness is commonly ignored not only by the service users

themselves but also by people around them and even by health systems.

People with severe mental disorders, including schizophrenia, experience disproportionately higher rates of mortality^{6,7}, often due to physical illnesses such as cardiovascular diseases, metabolic diseases, and respiratory diseases⁸. The mortality gap results in a 10-25 year life expectancy reduction in these patients^{4,5,9-11}. For people with schizophrenia, mortality rates are 2 to 2.5 times higher than the general population (9, 12).

Physical health conditions

There is evidence to suggest that people with schizophrenia have higher prevalence rates of cardiovascular problems and obstetric complications (in women). There is also good evidence that they are more likely to become overweight, develop diabetes, hyperlipidaemia, dental problems, impaired lung function, osteoporosis, altered pain sensitivity, sexual dysfunction and polydipsia or be affected by some infectious diseases such as HIV, hepatitis and tuberculosis as compared with the general population¹³. Different factors contribute to premature death. Fig. 1 summarises the association of different proposed factors contributing to premature death among people with schizophrenia and other severe mental disorders.

Unhealthy life style and factors of risk

Heavy smoking is about 2-6 times more prevalent among people with schizophrenia as compared with the general population, with prevalence rates between 50 and 80%¹⁴. Even as compared with people with other severe mental illnesses, being a current smoker is 2-3 times more common among people with schizophrenia¹⁵. Particularly high rates of smoking are observed among patients hospitalised for psychiatric treatment¹⁶.

Patients with schizophrenia are often at greater risk for being overweight or obese, with estimated prevalence rates

between 45 and 55%^{12,14,17}. People with schizophrenia have demonstrated lower levels of physical activity and physical fitness than the general population, which may be due to the limited ability to be physically active, being overweight or obese, higher smoking rates and side effects from anti-psychotic medication¹⁸.

Impact of health and treatment systems

Institutionalization commonly robs service users of the space and the autonomy required for being mobile and physically active. Many institutions lack structured, balanced or individualised dietary regimes and people may gain weight and even become obese. Furthermore, many antipsychotic medicines increase appetite, and if not monitored regularly, may directly or indirectly contribute to substantial metabolic changes, which can lead to diabetes, hyperlipidaemia and hypertension¹⁹. Estimated prevalence rates for diabetes and hypertension in patients with schizophrenia are between 10 and 15% and between 19 and 58% respectively¹⁴.

The elevated physical health risks associated with schizophrenia and other severe mental illnesses indicate a stronger need for close and regular health monitoring. Paradoxically, people with severe mental illness receive less medical care for their physical problems as compared with others²⁰.

Being in good physical health is a crucial aspect for quality of life; however, it is known that people living with schizophrenia and other severe mental illnesses have a higher prevalence of physical diseases compared to the general population²¹. Promoting collaboration between mental and physical health is vital for improving care of people with severe mental illness. The diagnosis of physical conditions is commonly overshadowed by a psychiatric diagnosis and delayed diagnosis makes interventions less effective or even impossible²².

Mental and Social Health Problems

A common but harmful mistake is to identify people with schizophrenia simply as a clinical diagnosis. The inappropriate term “schizophrenic” is commonly used by the public and even by some care givers to refer to a person who is living with schizophrenia. This term eclipses the human and social nature of that individual, and renders them as purely a diagnosis. People living with schizophrenia experience discrimination and violations of their rights both inside and outside institutions. In everyday life they face major problems in the areas of education, employment, and access to housing. As previously mentioned, even access to health services is more challenging.

People living with a severe mental disorder are also likely to suffer from other mental disorders such as depression and substance abuse. Lifetime prevalence of suicide among those living with a severe mental disorder is around 5% which is much higher than that in the general population^{23, 24}. Higher prevalence of substance use among people with schizophrenia along with some other factors contributes to the higher reported violent activity among them and to their higher rates of victimization alike²⁴. People with severe mental illnesses, including schizophrenia are also more likely to be homeless, unemployed, or living in poverty^{25,26}.

Interventions

In many countries efforts have begun to better improve the physical health of people with schizophrenia, whilst simultaneously encouraging the social and education sector to provide better access to service for people with severe mental illness. Treatments should not be limited to pharmacotherapy. Non-pharmacological psychosocial interventions are gaining an increasing importance and should be considered an adjunctive component of mental disorder management. Psychosocial interventions are also effective at preventing some of the side effects of antipsychotic medications. A meta-analysis has shown the enduring effects of a range of non-pharmacological interventions at reducing antipsychotic-induced weight gain, namely individual or group interventions, cognitive-behavioural therapy and nutritional counselling²⁷.

Discussion

The severity of disability in general reflects the interaction between features of a person and features of the society. Disability and morbidity experienced by people living with schizophrenia are not purely caused by brain pathology. Similarly, poor physical health and premature death are consequences

of interactions between people with schizophrenia and a society socially and functionally biased towards the population living with severe mental disorder. People with schizophrenia die earlier not because schizophrenia per se is fatal but rather because of the discrimination and lack of access to good health services, regular monitoring for other risk factors for health and physical diseases, and poor family and social support. A disempowered person with schizophrenia becomes incapable of self-care as well.

The Way Forward

For decades, we have been rightfully advocating for “no health without mental health”. This has been a popular slogan and is still valid. However, as coverage of mental health services has escalated, we have become more concerned about poor quality services worldwide. The time has arrived to call for “no mental health without physical health” as well³¹. Realizing this wish requires serious efforts from all stakeholders.

Our knowledge of mortality among people with severe mental illness and its correlates in low and middle income countries (LAMICs) is very limited. In a 2007 review, 86% of such studies came from industrialized countries³². In high income countries health literacy is higher, better quality services are available and there is overall better monitoring of the institutions and a greater frequency of regular check-ups for physical health of people with mental illness. The situation is expected to be much worse in low and middle income countries where the resources are poor, the institutions are poorly managed and access to sound mental health care and physical care is limited. WHO has started fresh evidence reviews and is sharing information on these important issues.

Many of WHO’s ongoing programmes also contribute to paving the way towards recovery of people with severe mental disorders including schizophrenia.

WHO’s Mental Health Action Plan³³, endorsed by the World Health Assembly in 2013 envisions and plans for all different aspects of services required to provide a healthy life for people living with mental disorders including

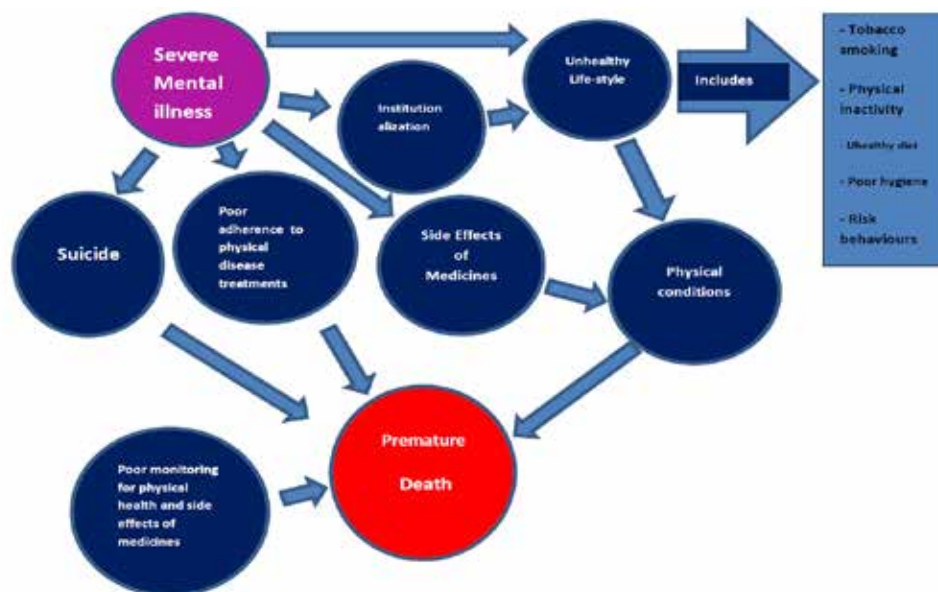


Fig.1. Proposed associations of different factors leading to premature death among people with severe mental illness.

We are sharing two examples of services that integrate different aspects of health and are summarized in boxes 1 and 2.

Box 1. The example of Fountain House²⁸

Fountain House, based in the US but with a global reach, has already developed an initiative which is community based, recovery oriented and at the same time very sensitive about the general well-being and physical health of the service users.

Their reports point to a high level of success and satisfaction of the service users and to “reversing the trend” in this regard and “Bringing hope to mind”. The programmes are comprehensive. They include wellness, education, employment and housing. Their meticulous concern about the physical health of the service users is reflected across many of their reports of activities and achievements. The “Health Home” of their Sidney Baer Centre is a good example of responding to this commonly ignored need.

Box 2. The chain free initiative in Mogadishu^{29, 30}

The “chain free initiative” in Somalia is an example of scaling up a community oriented service model in a poor resource country. WHO/EMRO started this low cost programme in Mogadishu and then expanded to similar contexts. The programme includes three phases: Phase 1. (Chain-free hospitals) includes removing the chains, and reforming the hospital into a patient friendly and humane place with minimum restraints. Phase 2. (Chain-free homes) organizing mobile teams and home visits, removing the chains, providing family psycho-education, and training family members on a realistic, recovery-oriented approach. Phase 3. (Chain-free environments) removing the “invisible chains” of stigma and restrictions affecting the human rights of persons with mental illness, and respecting the right to universal access to all opportunities with and for persons with mental illness, empowering and supporting the service users and ex-service users by mobilizing communities to provide them with job opportunities and shelter. The programme, which followed a results-based management approach, improved the situation in the psychiatric ward, and increased the number of those receiving services through home visits and outpatient visits. More and more ex-patients are now living and working in a community that is now more aware about the right of people with severe mental illness. The teams at the same time started to improve the service users’ nutrition and provided them with treatment of physical conditions including TB.

schizophrenia. The global plan emphasizes that persons with mental disorders should be able to access, without the risk of impoverishing themselves, essential health and social services that enable them to achieve recovery and the highest attainable standard of health. WHO promotes global actions using guidelines that are not only based on evidence but also observe the human rights of service users, which is why obtaining recovery has been observed as one of the favourable outcomes of access to services.³³

The Mental Health Gap Action Programme of WHO³⁴ and its Intervention Guide³⁵ are examples of WHO’s new approach in emphasizing

psychosocial interventions in addition to pharmacotherapy and in terms of a better focus on the health of service users in its totality. The revision of mhGAP-IG is underway and the updated version will be published in 2015. The updated version will provide us with guidelines that can further assure that harm is reduced to its minimum and benefits are maximized in terms of a holistic approach to service users’ health.

The Quality Rights Project of WHO and its checklist provides a good opportunity for monitoring the quality of services for people with mental illness including schizophrenia³⁶.

There are a range of actions that could be taken by different stakeholders; examples are summarized here:

People with schizophrenia: Exercising self-care and demanding their rights, including the right to comprehensive health care. Participation in decision-making and implementation of programmes on mental health.

Families: Supporting and empowering the family members of people with schizophrenia

Communities and civil societies: Empowering the people with schizophrenia, removing stigma and discrimination, respecting their rights, facilitating inclusion in economic and social activities, as well as including socially and culturally appropriate supported employment. Meeting the families’ physical, social and mental health needs. Working with local agencies to explore employment or educational opportunities, based on the person’s needs and skill level.

Health sector: Taking certain measures such as downsizing and ultimately terminating institutionalization. Also providing high quality physical services and regular monitoring for risk factors and side effects of treatments, tackling unhealthy life styles, as well as identifying and treating common chronic physical conditions among people with schizophrenia. Adoption of smoking cessation strategies for and with service users and promoting smoke free service environments. Coordinating with the service users as well as social, education, housing, employment and other sectors.

Social sector: Empowering and supporting people with schizophrenia to obtain education, employment and housing as well as coordinating with health and other sectors.

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LIVING BEYOND SCHIZOPHRENIA— RECOVERY IS POSSIBLE

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In the twentieth century the traditional dogma of the field of mental health was that a diagnosis of schizophrenia led to a lifetime of deterioration. In essence, schizophrenia was seen as a life sentence of mental health decline. The myth was that most people with schizophrenia were “deteriorating with schizophrenia”, in contrast to the current fact that many people with schizophrenia can recover—and are “living beyond schizophrenia”. While there are many definitions of recovery from schizophrenia, an early, succinct definition of recovery was, “the development of new meaning and purpose in one’s life as one grows beyond the catastrophe of schizophrenia” (Anthony, 1993). While diagnosticians of the 20th century believed that the most common outcome of schizophrenia was “acute exacerbations with increasing deterioration between episodes” (American Psychiatric Association, 1987), the more recent quantitative and qualitative research findings suggest otherwise (Anthony & Ashcraft, 2010).

Two important developments occurred late in the twentieth century that have led to the understanding that recovery was possible. One factor was the writing of people with psychiatric diagnoses, including schizophrenia. Beginning in the 1980s first person accounts of people’s recovery from severe mental illnesses began to appear regularly in the literature (e. g., Deegan, 1988; Leete, 1989; Mead & Copeland, 2000). Also qualitative studies of people’s recovery experiences became commonplace (e. g., Jacobson, 2001; Jenkins et al., 2007; Spaniol et. al, 2003).

The second development supporting the factual basis of recovery from schizophrenia was the long term, followup studies of people with schizophrenia that were being conducted

all over the world. Harding and her colleagues reviewed a number of these long term research studies and reported that a deteriorating course for severe mental illnesses, including schizophrenia, was not the norm (Harding, 1994; 2003). As a result of these two developments there is now both anecdotal and empirical support for the fact that there can be healing and growth after a person has been diagnosed with schizophrenia. People with schizophrenia are no longer defined by their schizophrenia diagnosis and symptoms, but rather by their long term success and satisfaction in numerous living, learning, working and socializing roles. People with schizophrenia can experience a meaningful life after diagnosis, not a deteriorating life.

Based on this new understanding of recovery, now in the twenty first century we find a revolution brewing in the field of mental health. It is a revolution in vision—in what is believed possible for people diagnosed with schizophrenia. In the previous century it was thought that people living with schizophrenia must endure a lengthy duration of severe disability, with a deteriorating course over their lifetime. New empirical and anecdotal evidence indicates that this belief was erroneous. We are increasingly convinced by this current anecdotal and empirical data that recovery from schizophrenia is possible for many more people than was previously believed. Furthermore, it appears that much of what we thought was the chronicity of schizophrenia was due to the way society and the mental health system treated people with schizophrenia, and not the illness itself. Where once there was little hope for much more than a deteriorating, long term disability for people diagnosed with schizophrenia, there is now a research based hope for a meaningful life beyond schizophrenia. A vision of the possibilities of recovery changes how we treat people with schizophrenia.

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LIVING WITH SCHIZOPHRENIA - CALL TO ACTION

Living with schizophrenia is the theme of World Mental Health Day 2014, because we want to bring hope to the 26 million people worldwide affected by schizophrenia, a number which doubles when families and carers are included.

Schizophrenia is an illness that typically starts in adolescence and may affect well-being, making it harder for some people to reach their full potential. But, we know that up to 50% of people affected by schizophrenia, if not more, will eventually have a good outcome if they receive the appropriate help. Recovery is a journey and recovery is possible. This is illustrated by the personal stories we have had the privilege of sharing in this year's World Mental Health Day material.

To ensure that individuals achieve recovery we call for the global health community, governments, donors, multilateral agencies, and other mental health stakeholders, such as professional bodies and consumer groups, to do all that they can to support people experiencing the symptoms of schizophrenia and their families, especially as the protection and treatment of people with schizophrenia is recognised by the United Nations as a fundamental human right.

A major barrier to achieving recovery is social attitude and the stigma associated with mental illness and schizophrenia. We call on every citizen to rise above this prejudice and be your neighbour's keeper. Access to housing, education, leisure activities, family life and companionship continues to be difficult for many people with schizophrenia. We call on people who provide services to ensure that access to all the things that everybody takes for granted to live a good life are provided for people with schizophrenia, just like for everybody else.

Early diagnosis and access to good mental and physical health care is important and collaboration between specialists, family doctors, people with schizophrenia and their families is an essential component of delivering the best quality interventions. Policy makers and politicians need to stand up and be counted, so that they produce appropriate policies and laws to ensure parity of physical and mental health care.

Spirituality can play an important role in helping people maintain good mental health and live with or recover from mental health problems and this should be supported. NGO's play a role and should actively seek out those people with schizophrenia in the community to actively support them and enable the building of networks and social connections with others.

To make positive change we require a focus on good quality research, so that we can adopt truly evidence based practice. We need effective medications with less side effects, access to psychological and social therapy, smoking cessation, access to exercise and all those things that support healthy lifestyles and contribute to recovery in schizophrenia.

World Mental health Day is the flagship event of WFMH, the oldest mental health advocacy organisation in the world. It provides a focus for each and every one of us to advocate for better mental health and to address the stigma that can limit people's development whether you are a member of WFMH or not.

World Mental Health Day is celebrated by many groups, large and small, all over the world on 10th October. These events bring mental health to everybody's consciousness and bind us together. Let's share our activities. Send your photographs, event programmes and summaries of what you have achieved to wmhday@wfmh.com so we can celebrate one another's efforts, learn from each other and support one another.

SECTION VI

WORLD OF THANKS

As we celebrate the 2014 World Mental Health Day campaign, we also celebrate the incredible people living with Schizophrenia. We have to stop and reflect on the pain, struggles and strength these people experience with the illness and how they overcome its hold on them to reach a point in life where they feel happy and comfortable in their own skin. We thank all of those people who have spoken up about their experience of living with schizophrenia and hope that this will encourage others to speak out and stand up and find their own recovery.

Schizophrenia is an illness that has followed mankind throughout history yet still today it is so misunderstood and treatment has only just begun to be person-centered and with an aim of recovery. The 2014 campaign will give you information on what schizophrenia is, how early intervention and holistic care affect how people live with schizophrenia, the role of prevention and promotion, social inclusion and many personal stories to help you understand how people deal with the diagnosis and how they have reached recovery.

Each year as we begin production of the material, we find ourselves working with such amazing professionals that are willing and able to contribute to the campaign - therefore we would like to extend a very genuine thank you to all those writers involved in this year's material – Jeffrey Geller, Janet Meagher, Bill MacPhee, David Crepaz-Keay, Dinesh

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